

Advance Care Planning in the Marital Context: Dyadic Analyses of Advance Directive  
Completion by Older Married Adults

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Completion by Older Married Adults

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## **Abstract**

Advance directive completion is associated with higher quality care at the end of life and increased odds of receiving hospice care and of dying at home. Researchers seeking to understand why some older adults complete advance directives while others do not tend to treat the decision as an individual choice. This individualistic approach fails to account for the interdependent nature of many health decisions made by married persons. I developed a relational model of end-of-life planning adapted from the transtheoretical model of behavioral change (TTM) to more accurately represent advance directive completion by married older adults

To evaluate this relational model, I investigated advance directive completion by older married adults as a dyadic process through two interrelated studies. First, with quantitative couple data from the Health and Retirement Study, I examined the relationships between husbands' and wives' advance directive completion and each spouse's age, education, health status, prior hospitalization or outpatient surgery, and regular health care provider using the Actor-Partner Interdependence Model. These variables have been found to be associated with higher odds of advance directive completion in previous studies, but this is the first study to test whether these predictors also exert spousal effects. I found that personal and spousal age and education were positively associated with advance directive completion. Those whose spouses were in poorer health were less likely to have advance directives. Men's hospitalization or outpatient surgery, but not women's, was related to an increased probability of having an advance directive for both themselves and their spouses. Women who had a regular source of health care were more likely to have advance directives, but whether a man had a regular health care provider did not affect the likelihood of advance directive completion for either spouse.

Taken as a whole, these findings support the proposition underlying the relational model that advance directive completion is associated with both personal and spousal attributes and encounters with health care providers.

Second, I interviewed eight married adults (four couples) who had engaged in end-of-life planning including completing advance directives. Through these interviews, I was able to assess whether participants' accounts of the events leading up to their end-of-life planning corresponded to the decisional stages described in the proposed relational model. I also observed to what extent they presented their motivations and decisions as independent of or interdependent with their spouses' planning. Advance directive completion was just one part of a broader end-of-life planning process. Participants' described a gradual process of growing awareness of and interest in end-of-life planning, obstacles that had to be overcome, and triggering events that prompted concrete steps toward completion of advance directives. Many of the factors influencing participants' progress up to and through end-of-life planning were interpersonal, such as spouses' health and the illnesses and deaths of parents and parents-in-law. Progressive movement toward end-of-life planning by husbands and wives was also frequently mutually influenced. Although participants' descriptions were substantially consistent with the relational model I initially developed, I made several adjustments in light of the interview data.

In combination, these two studies support the proposition that end-of-life planning by older married adults is an interdependent process shaped by both personal and spousal factors. These influences were present at individual, interpersonal, and organizational context levels. Future research into why older adults complete advance directives should account for the dyadic and contextual nature of these decisions when made by married adults, as should public education efforts and interventions promoting end-of-life planning.

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## **Chapter 1**

### **Introduction**

#### **Advance Care Planning Overview**

Approximately 40% of older adults in the United States<sup>1</sup> require surrogate decision making at the end of life because they become unable to formulate or articulate instructions about the medical treatment they do or do not wish to receive (Silveira, Kim, & Langa, 2010). When no information about a person's preferences is available, the general legal presumption in such cases is that the individual would choose to receive all medical care necessary to sustain life (Institute of Medicine [IOM], 2015). However, if a person adequately communicates his or her preferences about future life-sustaining treatment while still competent, this presumption no longer applies and the patient's expressed wishes should guide medical decisions. The process of reflecting on and informing loved ones and health care providers about how future medical decisions should be made in the event of incapacity is called advance care planning (ACP) (Pearlman, Cole, Patrick, Starks, & Cain, 1995).

ACP is an ongoing process of contemplating one's wishes about medical care, discussing preferences with others, documenting instructions, and periodically revisiting and revising one's choices as circumstances change (Sudore et al., 2008). ACP often results in a legal document called an advance directive, the format of which varies but usually consists of two parts: a living will and a durable power of attorney for health care (IOM, 2015). The living will section of an advance directive allows individuals to state what medical treatments they would or would not wish to receive under certain conditions such as a persistent vegetative state or irreversible and

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<sup>1</sup> Although advance directives and other forms of advance care planning exist in many countries, the focus of this dissertation is on advance care planning in the United States.

severe cognitive impairment. The durable power of attorney for health care is used to nominate one or more health care proxies to act on one's behalf in the event of incapacity. Although not the focus here, end-of-life care instructions may also be documented as Do-Not-Resuscitate Orders (DNR) or Physician Orders for Life-Sustaining Treatment (POLST) (IOM, 2015).

**Benefits and limitations of advance directives.** The primary purpose of ACP is to ensure that individuals who are unable to make medical decisions nonetheless receive care consistent with their preferences. Patients' instructions expressed in their advance directives are generally honored by health care providers (Flo et al., 2016; Silveira et al., 2010). Almost all individuals who complete advance directives request only limited or comfort care (Silveira et al., 2010). Not surprisingly then, advance directive completion is associated with a reduction in life-sustaining interventions at the end of life, particularly intubation and cardiopulmonary resuscitation (CPR) (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014; Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007; Tschirhart, Du, & Kelley, 2014). Patients who possess advance directives are more likely to be admitted to hospice and to receive hospice care for longer periods of time (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013; Brinkman-Stoppelenburg et al., 2014; Greiner, Perera, & Ahluwalia, 2003; Teno et al., 2007). Hospice is associated with higher quality end-of-life care (Wright et al., 2016).

Psychological benefits of ACP for family decision makers have also been documented (Wright et al., 2008). At least one third of those who make treatment decisions on behalf of incapacitated patients report experiencing anxiety, stress, or other negative emotions as a result of making these difficult decisions on behalf of their loved ones (Wendler & Rid, 2011). Knowing what the person would have wanted through verbal or written ACP has been found to

reduce these negative effects (Abbott, Sago, Breen, Abernethy, & Tulsky, 2001; Tilden, Tolle, Nelson, & Fields, 2001; Wendler & Rid, 2011).

Another way that ACP may improve quality of death is to reduce rates of hospitalization at the end of life. Although there are important cultural variations in the definition of a “good death” (Mak & Clinton, 1999; Tong et al., 2003; Walter, 2003), the majority of chronically or terminally ill persons would prefer to spend their remaining time at home rather than in a hospital (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013; Higginson & Sen-Gupta, 2000; McPherson, Wilson, & Murray, 2007). Advance directives have been found to lower the odds of dying in the hospital, but do not seem to reduce hospital admissions in the final months of life (Bischoff et al., 2013; Brinkman-Stoppelenburg et al., 2014; Kessler & McClellan, 2004; Silveira et al., 2010; Silveira, Wiitala, & Piette, 2014; Teno et al., 2007). Among patients at high risk of death, written ACP decreases the odds of intensive care unit (ICU) admission and is associated with shorter ICU stays (Khandelwal et al., 2015). Bischoff and colleagues (2013) theorized that patients who have engaged in ACP may be just as likely to be hospitalized, but more likely to be discharged prior to death rather than remain hospitalized during their final days. Because advance directives do not generally take effect until certain criteria are met (e.g., the patient has been determined by physicians to lack mental capacity and have little chance of recovery), written ACP may not influence hospitalization until the very end of life (Teno, Stevens, Spornak, & Lynn, 1998).

The failure of advance directives to reduce hospitalizations has limited the economic effects of ACP. Researchers have generally concluded that advance directives have little to no impact on end-of-life care costs (Fonk, Davidoff, Lutzow, Chesley, & Mathiowetz, 2012; Garrido, Balboni, Maciejewski, Bao, & Prigerson, 2015; Kelley, Morrison, Wenger, Ettner, &

Sarkisian, 2010; Prendergast, 2001; Teno et al., 1997). One study did find written ACP lowered Medicare expenditures, but only in regions where average end-of-life costs were particularly high (Nicholas, Langa, Iwashyna, & Weir, 2011).

### **Efforts to Promote ACP**

Given the actual and hoped for benefits of ACP, a concerted effort has been made in the United States to encourage advance directive completion and end-of-life care discussion, particularly by older adults. Federal law requires all hospitals, long-term care facilities, hospices, home health agencies, and health maintenance organizations that receive Medicare or Medicaid funding to provide written information about advance directives at the time of admission or enrollment and to document advance directives in patients' medical records. (*Patient Self-Determination Act* [PSDA], 1990). Information about advance directives is provided on the Medicare.gov website and in the annual *Medicare and You* publication. End-of-life planning has been covered for several years by Medicare as part of a one-time preventive health physical exam (U.S. Government Accountability Office [GAO], 2015). In 2016, the Centers for Medicare and Medicaid Services (CMS) began permitting physicians and other qualified health care providers to bill Medicare for time spent with patients discussing medical preferences or completing advance directives during any consultation (Sabatino, 2015).

Government efforts to encourage ACP are bolstered by dozens of private sector programs that provide information and tools to enable individuals to engage in ACP (IOM, 2015). High-profile media stories such as the legal battle waged in 2005 by Terri Shiavo's family to remove life support also periodically raise awareness about ACP and motivate some to complete advance directives (Sudore, Landefeld, Pantilat, Noyes, & Schillinger, 2008).

Approximately half of U.S. adults age 65 and older have advance directives (Pew Research Center, 2009; Rao, Anderson, Lin, & Laux, 2014). If one waits until after death to determine whether a person ever completed an advance directive, prevalence estimates for older adults are closer to 75% (Koss & Baker, 2016; Silveira et al., 2014). Despite dozens of studies on the topic – many of which are discussed in Chapter 2 – the reasons why some people complete advance directives while others postpone or never engage in written ACP are still little understood.

### **ACP in the Context of Marriage**

Most of the research on advance directive completion has treated ACP as an individual health behavior. Increasingly however, scholars have highlighted the importance of understanding the roles that family members such as spouses and adult children may play in ACP (Boerner, Carr, & Moorman, 2013; Carr, Moorman, & Boerner, 2013; Kahana, Dan, Kahana, & Kercher, 2004; Moorman, Carr, & Boerner, 2014; Singer et al., 1998; Woosley, Danes, & Stum, 2016). This dissertation adopts a novel approach to addressing the question of what differentiates those older adults who complete advance directives from those who do not by taking into account the characteristics, motivations, and ACP behaviors of husbands and wives.

There has been growing interest in studying aging in the context of marriage and family over the past few decades (Allen, Blieszner, & Roberto, 2000). The marital relationship in particular is a potentially important social context in which ACP takes place because medical decisions frequently have consequences for spouses and are often the result of consultative or joint decision making processes (Haley et al., 2002; Rettig, 1993). Spouses and partners exert informal control to regulate and shape life trajectories, behaviors, and decisions (Elder & Shanahan, 2006).

The main thesis of this dissertation is that the current approach of studying advance directive completion as largely an individual health behavior is inadequate, at least for married older adults, because it fails to account for spousal influences and interdependence. To test this proposition, I investigated advance directive completion by older married adults in two ways. First, I analyzed quantitative couple data from the Health and Retirement Study (HRS). Using the Actor-Partner Interdependence Model (APIM) (Kenny, Kashy, & Cook, 2006), I examined the relationships between personal and spousal independent variables and the advance directive status of husbands and wives. To my knowledge, this is the first study to dyadically model advance directive completion by older married adults using the APIM. Second, I interviewed older married adults who had engaged in end-of-life planning, including ACP. Through these interviews, I gained a deeper understanding of the events and circumstances in both their own and their spouses' lives that motivated, delayed, or triggered their advance directive completion. I also explored to what extent the processes leading up to end-of-life planning by the spouses were independent or interdependent.

### **Theoretical Framework**

I began with the transtheoretical model of behavioral change (TTM) as my initial theoretical framework. Like other health behaviors that have been described using the TTM (e.g., smoking cessation, moderate alcohol consumption, and exercise) a person's willingness and ability to complete an advance directive is likely influenced by perceived vulnerability, self-efficacy, obstacles, and benefits (Fried, Bullock, Iannone, & O'Leary, 2009). The TTM has been used to describe the process leading up to advance directive completion and has served as the basis for several intervention programs to promote ACP (Fried et al., 2009, 2010, 2012; Medvene, Base, Patrick, & Wescott, 2007; Moorman & Inoue, 2012; Westley & Briggs, 2004).



The TTM defines individual health behavioral change as a series of five steps or stages: Precontemplation, Contemplation, Preparation, Action, and Maintenance (Prochaska et al., 1994). Someone in the Precontemplation stage has no intention of engaging in a behavioral change in the near future. A person who begins to consider making a change and how to do so moves into the Contemplation stage. The Preparation stage is characterized by concrete actions in anticipation of engaging in behavioral change in the near future. Making the change moves an individual into the Action stage, after which he or she strives to maintain the newly adopted behavior. Failure to sustain a behavioral change may cause a person to cycle out of the Maintenance stage back to an earlier step in the process.

Another important concept in the TTM is decisional balance, or the weighing of the perceived advantages and disadvantages of adapting a new behavior (Prochaska et al., 1994). This calculation involves considerations of gains and losses for both the self and significant others, self-approval or self-disapproval, and the positive or negative judgments of others. Shifts in the decisional balance occur as one moves through the stages of change. In the Precontemplation stage, the perceived disadvantages of adopting a new behavior outweigh the advantages. As the person moves through the stages toward Action, the perceived advantages gradually outweigh the disadvantages. Once a new behavior is adopted, it will be maintained as long as the costs of yet another change are believed to be greater than the benefits of sustaining the current practice.

There are some obvious differences between ACP and other health behaviors, particularly those that require ongoing commitments and the development of new routines or lifestyles. Nevertheless, evidence suggests that the TTM is a useful model for understanding the motivations, barriers, and timing of written ACP, particularly when advance directive completion

is understood to be part of an ongoing process involving reflection, discussion, documentation, and revision (Fried et al., 2010, 2012; Medvene et al., 2007; Moorman & Inoue, 2012; Westley & Briggs, 2004). The TTM is also an appropriate theoretical base from which to begin to study spousal influences on ACP because it recognizes the role of significant others in the decisional balance. However, the model nonetheless conceives of behavioral change as an individual decision-making process. My central argument is that, for older adults who are married, willingness and ability to complete an advance directive is determined by both individual and spousal factors. Furthermore, one's own progression through the stages of change toward and through action may be aided or hindered by a spouse's progression through these stages, and vice versa. I therefore developed and tested the usefulness of a relational model of ACP by older married adults based on the TTM. This proposed relational model is presented and described in more detail in Chapter 3.

### **Organization of the Dissertation**

This dissertation is organized into nine chapters. Chapter 2 is a literature review surveying previous research on the factors associated with advance directive completion. In Chapter 3, I outline the development of advance directives and how this history has contributed to the emphasis on individualism in ACP research. I also offer several critiques and alternative theoretical models for medical decision making, present the case for studying advance directive completion by married older couples as an interdependent process, and develop a relational model based on the TTM. Chapters 4 and 5 describe the methods and results of the quantitative study. The methods and results of the qualitative study are presented in Chapters 6 and 7. Chapter 8 offers a synthesis and discussion of the qualitative and quantitative findings. I end by reflecting on implications and future directions in Chapter 9.

## **Chapter 2**

### **Literature Review**

This chapter provides an overview of previous research on advance directive completion. The purpose of this literature review is to catalogue the extent to which the underlying reasons for engaging in written ACP have been studied at various levels of analysis (policy, health and legal services, family, and individual) and what factors have and have not been found to be associated with advance directive completion.

#### **Policy**

In Chapter 1, I briefly described the main laws, government programs, and private sector efforts designed to promote ACP through public education. The one that has received the most attention from researchers is the Patient Self Determination Act (PSDA) (1990), a federal law that requires covered health care providers to offer written information about advance directives to patients and to document advance directives in patients' medical records.

Advance directive prevalence has steadily increased since the PSDA was enacted (GAO, 2015; Hanson & Rodgman, 1996; Hopp & Duffy, 2000; Resnick, Schuur, Heineman, Stone, & Weissman, 2009; Silveira et al., 2014). However, caution should be exercised in attributing growth in rates of written ACP directly to the PSDA mandate to inform patients about advance directives. The general conclusion of studies that have examined the impacts of the PSDA is that the law has not directly led to a substantial increase in completion of advance directives, but has improved the documentation of advance directives in patients' medical records (Bradley, Wetle, & Horwitz, 1998; Prendergast, 2001; Teno et al., 1997; Terry & Zweig, 1994).

Knowledge of advance directives is positively associated with having one, whereas lack of understanding or familiarity with ACP is a commonly cited barrier (Alano et al., 2010; Ejaz,

2000; Fried et al., 2009; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998). However, providing information is not sufficient by itself to substantially raise rates of advance directive completion. The limited effectiveness of promoting ACP through public education has been illustrated by the generally disappointing results of intervention programs that only provide information about and general encouragement to engage in ACP (High, 1993; Prendergast, 2001; Rubin, Strull, Fialkow, Weiss, & Lo, 1994; Teno, Lynn, Wenger, et al., 1997; Wissow et al., 2004). In contrast, interventions that combine information with follow up and one-on-one counseling or assistance – preferably over the course of multiple interactions – have been more successful (High, 1993; Patel, Sinuff, & Cook, 2004; Pearlman, Starks, Cain, & Cole, 2005; Tamayo-Velázquez et al., 2010). As discussed in the next section, older adults commonly receive this information and assistance from health care providers and attorneys.

## **Health and Legal Services**

**Interactions with health care providers.** Opportunities to interact with health care providers are associated with increased likelihood of engaging in written ACP. Those with a regular source of health care have been found to be more likely to have advance directives (Rao et al., 2014). Recent hospitalization and/or current or recent residence in a long-term care facility are also associated with higher odds of advance directive completion (Alano et al., 2010; Bischoff et al., 2013; Bradley et al., 1998; Carr, 2012c; Carr & Khodyakov, 2007; Ha & Pai, 2012; Hirschman, Abbott, Hanlon, Bettger, & Naylor, 2011; Koss & Baker, 2016; McCarthy et al., 2008).

Many of the studies considering factors at the health care system-level focus on the face-to-face interactions between patients and health care providers, particularly whether and when physicians initiate or encourage ACP. Both patients and physicians tend to believe that doctors

should take the lead in initiating discussions about end-of-life planning (Dow et al., 2010; Glaudemans, Charante, & Willems, 2015; Johnston, Pfeifer, & McNutt, 1995). Although many patients are interested in discussing and documenting their treatment preferences and would like these conversations to occur early in the physician-patient relationship or disease process, doctors are frequently hesitant to raise the subject with their relatively healthy patients (Johnston et al., 1995). As a result, older patients who are terminally ill, particularly cancer patients, and those with mild to moderate dementia are likely to receive assistance with ACP from their physicians, but ACP is not often part of the care provided to most older adults despite the general consensus among doctors and patients that end-of-life care planning would be beneficial (Glaudemans et al., 2015). It remains to be seen how the new Medicare reimbursement for assisting patients with ACP will change doctors' practices.

Reluctance on the part of health care providers to initiate ACP may be compounded by cultural differences. Doctors' comfort discussing end-of-life issues with ethnically diverse patients was the subject of a recent survey of more than 1,000 new physicians (Periyakoil, Neri, & Kraemer, 2015). Almost all respondents identified barriers to engaging in end-of-life discussions with patients who did not share their ethnic backgrounds, and more than 85% characterized such conversations as very challenging. Among the commonly identified barriers were language – including medical jargon – and physician ignorance about cultural beliefs and practices.

Patients' attitudes about health care providers have also been examined as potentially influencing ACP. The degree to which a person believes that physicians should make medical decisions for their patients has generally not been found to be predictive of advance directive completion (Carr, 2012c; Carr & Khodyakov, 2007; Huang, Neuhaus, & Chiong, 2016),

although participants in one study who disagreed with the assertion that a doctor should make important health care decisions were more likely to have engaged in written ACP (Su, 2008). Mistrust in the medical system has also been identified as a barrier to advance directive completion, particularly for African Americans and other minorities who have been historically underserved and poorly treated (Bullock, 2006; Bullock, McGraw, Blank, & Bradley, 2005; Fried et al., 2009; Johnson, Kuchibhatla, & Tulsky, 2008).

Provider- and institutional-level factors have been shown to influence advance directive completion by residents of long-term care facilities. Commonly cited barriers include staff reluctance to discuss end-of-life issues with residents, employees' lack of knowledge or experience assisting others with ACP, uncertainty among staff regarding the legal implications of planning documents, and human resource limitations such as lack of time, high employee turnover, and understaffing (Flo et al., 2016). In studies reporting results of institution-based interventions, factors that are often cited as contributing to successful promotion of ACP are staff education and support as well as standardization of ACP responsibilities and documentation (Flo et al., 2016).

**Interactions with legal professionals.** Although studied less often, interactions with legal professionals may influence written ACP because advance directives are frequently completed with the assistance of an attorney as part of estate planning (Hirschman, Kapo, & Karlawish, 2008; Kelly, Masters, & Deviney, 2013; Malcomson & Bisbee, 2009; Pollack & Williams, 2010; Thorevska et al., 2005). The few studies that have included estate planning as an independent variable find that having a will is highly predictive of having an advance directive (Carr, 2012c; Kelly et al., 2013; Su, 2008).

## **Family**

The empirical studies looking at familial influences on advance directive completion have considered the potential effects of family structure (i.e., marital and parental status), ACP by family members, family member characteristics, relationship quality, and experiences of loved ones' illnesses and deaths.

**Family structure.** Being married could conceivably influence end-of-life planning either positively or negatively. Those who are married may be less likely to complete advance directives because they believe (rightly or wrongly) that their spouses can make decisions on their behalf and know what their wishes would be. Divorce or widowhood could trigger ACP by prompting new estate planning in response to changed circumstances. The death of a spouse may also make the surviving spouse more aware of the importance of end-of-life planning. On the other hand, unmarried individuals may have more difficulty finding people willing and able to serve as health care proxies, particularly if they do not have children or if relationships with those children are strained.

Findings on the association between marital status and ACP are mixed, with some studies observing that married older adults are less likely to have advance directives than those without partners (Bischoff et al., 2013; Hopp, 2000; Teno et al., 2007), others suggesting that marriage increases the odds of written ACP (Carr & Khodyakov, 2007; Rao et al., 2014), and a number of studies finding no significant relationship (Boerner et al., 2013; Carr, 2011, 2012c; Huang et al., 2016; Pollack & Williams, 2010). When marital status is broken down into multiple categories, widowhood appears to increase the likelihood of advance directive completion, although this finding is not universal (Carr et al., 2013; Ha & Pai, 2012; Koss & Baker, 2016; Resnick et al., 2009; Su, 2008).

Parenthood has been hypothesized to motivate older adults to complete advance directives in order to make end-of-life decisions easier for their offspring (Moorman et al., 2014). However, the evidence that parenthood increases the likelihood of engaging in written ACP is not overwhelming. Most studies have found no relationship between advance directive completion and the number of children a person has (Boerner et al., 2013; Carr, 2012b; Woosley et al., 2016). Data from the Wisconsin Longitudinal Study (WLS) showed that having more children increased the likelihood of completing a living will, but there was no statistically significant relationship between the number of children and completing a durable power of attorney for health care (Carr, 2012c; Carr & Khodyakov, 2007). Also using WLS data, Su (2008) did not find that having one or more children significantly increased the odds of engaging in end-of-life health care planning.

**Family member ACP.** Having a family member who engaged in written ACP may increase the odds of having an advance directive. Allen and colleagues (2003) observed that nursing home residents were more likely to have advance directives if their family proxy decision makers had completed their own advance directives. Woosley, Danes, and Stum (2016) also found that, for participants in the WLS who had experienced the death of at least one parent, having a parent who had completed a living will was associated with engaging in more health care and financial planning actions.

**Family member characteristics.** Little research has been conducted to examine how the attributes of a spouse or other family members may be related to ACP. One study found that nursing home residents were less likely to have advance directives if their surrogate decision maker was highly religious (Allen et al., 2003). Another study found that having a caregiver who was Caucasian increased the odds of advance directive completion among patients diagnosed



with a terminal illness (Ho et al., 2016). In a qualitative dyadic study involving older veterans and their appointed surrogates, one identified barrier to ACP was the perception by one that the other was not comfortable or willing to talk about end-of-life matters (Fried, Zenoni, & Iannone, 2016). Although not directly related to ACP, a recent study tested how spousal health and education may influence patients' hospice enrollment (Ornstein et al., 2016). The authors found that having a spouse with lower educational attainment than one's own decreased the odds of receiving hospice care at the end of life, but spouses' health was not predictive of hospice enrollment.

**Relationship quality.** Persons with positive family relationships may be more likely to engage in ACP out of concern for loved ones or because of the availability of trusted family members to serve as health care proxies. Marital satisfaction appears to be positively associated with engaging in both written and verbal ACP by married adults (Carr et al., 2013; Moorman et al., 2014). In contrast, a small study of wives involved in an ACP intervention found that their level of reported marital commitment was unrelated to advance directive completion (Medvene, Patrick, & Wescott, 2002). Boerner and colleagues (2013) also found no significant relationship between spousal criticism, emotional support, or marital duration and written ACP, although emotional support from a spouse was associated with higher odds of engaging in end-of-life discussion.

Two studies have considered the potential link between the quality of parent-child relationships and parents' written ACP. In a New Jersey-based sample of older adults, better family functioning was associated with higher odds of engaging in ACP, but there was no significant relationship between written ACP and either positive or negative interactions with one's children (Boerner et al., 2013). In a study using WLS data, more frequent critical

interactions with adult children was found to be associated with lower odds of verbal and written ACP by married participants, but was not related to ACP by non-married participants (Carr et al., 2013).

**End-of-life experiences of loved ones.** Experiencing the death of a loved one – particularly if the death was difficult, unexpected, or painful – has been shown to increase the likelihood of having an advance directive (Amjad, Towle, & Fried, 2014; Carr, 2011, 2012c; Carr & Khodyakov, 2007). Participants in qualitative studies frequently report being influenced in carrying out their own ACP by the illnesses and deaths of friends and family (Carr, 2012a; Fried et al., 2009; Goff et al., 2015; Hirschman et al., 2008; Lambert et al., 2005; Singer et al., 1998). Making end-of-life decisions for another had also been shown to make people more willing to engage in their own end-of-life planning (Amjad et al., 2014; Jackson et al., 2009; Levi, Dellasega, Whitehead, & Green, 2010; Murphy et al., 1996). However, not all studies have found the experience of the death of another to be predictive of engaging in written ACP (Jackson, Rolnick, Asche, & Heinrich, 2009).

### **Individual Factors**

Most of the studies seeking to understand why some engage in written ACP while others do not focus on individual characteristics as potential predictors. Individual determinants of health behavior can be divided into predisposing, enabling, and need factors (Aday & Andersen, 1974).

**Predisposing.** Predisposing factors are pre-existing characteristics that influence the propensity of a person to engage in a health behavior. These include age, gender, race/ethnicity, education, religion, personality traits, and attitudes.

**Age.** Being older is consistently associated with greater odds of having an advance directive (Bradley et al., 1998; Butler et al., 2015; Carr, 2012b; Dow et al., 2010; GAO, 2015; Jackson et al., 2009; Kelly et al., 2013; Moorman & Inoue, 2012; Pollack & Williams, 2010; Rao et al., 2014; Sudore et al., 2008; Teno et al., 2007; Thorevska et al., 2005; Werth, Blevins, Toussaint, & Durham, 2002). Even in samples that are limited to older adults, advanced age increases the likelihood of written ACP (Alano et al., 2010; Bischoff et al., 2013; Harrison et al., 2016; Huang et al., 2016; Morrison et al., 1998; Resnick et al., 2009; Reynolds, Hanson, Henderson, & Steinhauser, 2008; Rosnick & Reynolds, 2003). Likewise, age at death is positively associated with having an advance directive (Gerst & Burr, 2008; Khosla, Curl, & Washington, 2015; Koss & Baker, 2016). The few studies that failed to find a relationship between age and written ACP tended to have small samples drawn from a single site or limited survey area (Allen et al., 2003; Boerner et al., 2013; Dobbs, Emmett, Hammarth, & Daaleman, 2012; Murphy et al., 1996; Smith et al., 2008).

Advance directive possession may be correlated with age because in many people's minds ACP is associated with being old. In qualitative studies, a common reason given by those who have not completed an advance directive is the self-perception of being too young to need one (Fried et al., 2016; Pollack & Williams, 2010). This mental association between age and ACP may also be held by health or legal professionals, making them more likely to bring up the topic with older patients or clients whom they perceive to be in greater need of engaging in end-of-life planning.

**Education.** Having more education has been found to make written ACP more likely across multiple studies involving adults of all ages as well as those limited to older adults, residents of nursing homes, and hospital patients (Boerner et al., 2013; Bradley et al., 1998; Carr,

2012b; Carr & Khodyakov, 2007; GAO, 2015; Ha & Pai, 2012; Hanson & Rodgman, 1996; Harrison et al., 2016; Hirschman et al., 2011; Huang et al., 2016; Koss & Baker, 2016; McCarthy et al., 2008; Mezey, Leitman, Mitty, Bottrell, & Ramsey, 2000; Moorman & Inoue, 2012; Muni, Engelberg, Treece, Dotolo, & Curtis, 2011; Murphy et al., 1996; Rao et al., 2014; Stelter, Elliot, & Bruno, 1992; Thorevska et al., 2005). Higher education may increase the likelihood of ACP because education is positively correlated with health literacy. Those with more education may be more familiar with ACP and therefore more likely to complete advance directives. Education is likewise correlated with economic status. Persons with greater accumulated wealth may be more likely to engage in estate planning which often also involves health care planning. However, a minority of studies failed to find a significant relationship between education and written ACP (Carr, 2011; Dobbs et al., 2012; Dow et al., 2010; Ejaz, 2000; Jackson et al., 2009; Kelly et al., 2013; Khosla et al., 2015; Smith et al., 2008; Su, 2008; Sudore et al., 2008).

***Race/ethnicity.*** Being white has been consistently found to be associated with higher odds of written ACP (Boerner et al., 2013; Hirschman et al., 2011; Muni et al., 2011). When specific race and ethnic groups are broken out, the most commonly studied are whites, African Americans, and Hispanics. Compared to whites, both African Americans and Hispanics are less likely to have advance directives (Bischoff et al., 2013; Butler et al., 2015; Carr, 2011, 2012b; Degenholtz, Arnold, Meisel, & Lave, 2002; Gerst & Burr, 2008; Hanson & Rodgman, 1996; Harrison et al., 2016; Huang et al., 2016; Hopp, 2000; Hopp & Duffy, 2000; Kwak & Haley, 2005; Mezey et al., 2000; Murphy et al., 1996; Pollack & Williams, 2010; Rao et al., 2014; Resnick et al., 2009; Rich, Gruber-Baldini, Quinn, & Zimmerman, 2009; Teno et al., 2007; Thorevska et al., 2005). A few studies have examined ACP among Korean Americans and found this population to also be less likely to have advance directives compared to whites (Ko & Lee,

2010; Murphy et al., 1996). Other race and ethnic groups are largely absent from the literature, either being excluded from samples or lumped into the catchall category of “Other.”

Proposed explanations for relatively low rates of ACP among African Americans include socioeconomic differences, mistrust of the health care system, religious beliefs, reluctance to acknowledge terminal prognosis, greater desire for life-sustaining treatment, lower levels of health literacy, lack of familiarity with advance directives or misunderstandings about the purpose of ACP, and doubt about the efficacy of ACP (Carr, 2011; Ladd, 2014; Sanders et al., 2016). However, empirical evidence supporting these explanations is limited. The belief that God determines the timing and circumstances of death was found in one study to largely explain disparities in written ACP (Carr, 2011). Another study found that the odds of having an advance directive were no longer statistically different for whites and African Americans once end-of-life preferences, beliefs about dying, mistrust in the health care system, and spiritually were controlled. The confidence intervals in both studies were large, so these findings could be a result of insufficient power to continue to detect race differences. In contrast, a larger nationally-representative study found that African Americans remained significantly less likely to have advance directives even after controlling for socioeconomic, religious affiliation and attendance, health attitudes, and other covariates (Huang et al., 2016). The underlying reasons for persistent gaps between whites and African Americans are still not well understood (Sander et al., 2016).

The reasons for lower rates of ACP among Hispanic adults are also not clear. Possible explanations include religious beliefs that encourage the prolongation of life, language barriers, a perception that adult children should ease the burdens on parents rather than vice versa, and an emphasis on informal decision-making processes that involve multiple family members (Carr, 2011). Huang and colleagues (2016) found that the odds ratio between white and Hispanic older

adults was no longer statistically different from one once religiosity, health values, and sociodemographic variables were controlled. However, the confidence interval was large and the lack of statistical significance could be due to insufficient power.

For those from non-Western cultural backgrounds, the focus on individual autonomy inherent in ACP may be inconsistent with preferences for family-centered decision making (Ko & Lee, 2010). It also may not be culturally acceptable to talk directly about issues related to illness and death.

**Gender.** Compared to age, race, and education, the relationship between gender and written ACP is less clear. Some studies offer evidence that women are more likely than men to complete advance directives (Alano et al., 2010; Bischoff et al., 2013; Butler et al., 2015; Huang et al., 2016; Pew Research Center, 2009; Rao et al., 2014; Resnick et al., 2009; Teno et al., 2007), while other studies indicate no gender difference (Allen et al., 2003; Boerner et al., 2013; Bradley et al., 1998; Carr, 2011, 2012b; Ha & Pai, 2012; Kelly et al., 2013; Koss & Baker, 2016; McCarthy et al., 2008; Mezey et al., 2000; Pollack & Williams, 2010; Thorevska et al., 2005). I came across only two studies that found being female lowered the odds of written ACP (Carr & Khodyakov, 2007; Moorman & Inoue, 2012). It is possible that gender differences reflect the fact that women are more likely to experience widowhood which is, as discussed earlier, associated with ACP. Women may also be more likely to talk about their end-of-life treatment preferences with others which may trigger documenting those wishes in advance directives.

**Religiosity.** Many religious denominations issue formal statements about end-of-life treatment options which may influence members' views and preferences. Participation in collective religious activities may bring older adults into contact with health care professionals, attorneys, or others knowledgeable about ACP (Kelly et al., 2013). On the other hand, making

decisions about future end-of-life care can seem unnecessary or even presumptuous to those who believe that God determines the time and place of each person's death (Rhodes et al., 2016).

Several studies have explored how religious affiliation, attitudes, or practices influence ACP, often with mixed results. Conservative Protestants and Catholics tend to be less likely to engage in ACP (Carr & Khodyakov, 2007; Huang et al., 2016), although in one study these effects became non-significant once religious beliefs were controlled (Garrido, Idler, Leventhal, & Carr, 2013). Data from the Coping With Cancer study failed to show that importance of religion or religiosity were related to ACP (Balboni et al., 2007; Smith et al., 2008). However, positive religious coping (i.e., the use of religious beliefs to respond to stress) was negatively associated with advance directive completion (Maciejewski et al., 2012; Phelps et al., 2009). Huang and colleagues (2016) found no relationship between frequency of religious service attendance and advance directive completion in national data, but attendance was associated with a higher likelihood of having a health care power of attorney in a state survey (Kelly et al., 2013).

***Attitudes about death.*** Making choices about end-of-life care necessarily involves contemplating one's own mortality. Not surprisingly then, death anxiety or a greater tendency to avoid thinking about death has been consistently found to be negatively associated with written ACP in both quantitative and qualitative studies (Carr, 2011, 2012b, 2012c; Carr & Khodyakov, 2007; Dobbs et al., 2012; Fried et al., 2016). Those who prefer more life-sustaining treatment or those who would choose to live regardless of health or functional limitations are also less likely to complete advance directives (Garrido et al., 2015; Huang et al., 2016; McCarthy et al., 2008).

***Personality.*** Certain personality traits may be more adaptive in difficult health situations or other circumstances under which ACP may be beneficial (Ha & Pai, 2012). Those who score

high in conscientiousness may also be more likely to engage in proactive planning generally. The few studies that have considered possible correlative relationships between personality and ACP found that higher levels of conscientiousness and agreeableness were associated with greater odds of written ACP (Carr, 2012c; Ha & Pai, 2012), while openness had little to no effect (Ha & Pai, 2012; Rosnick & Reynolds, 2003).

**Enabling factors.** Enabling factors facilitate individuals' access to assistance with engaging in a health behavior by providing a means or pathway to information and/or services. Examples of enabling factors include financial resources and health insurance coverage.

**Income and assets.** Greater household income has consistently been found to increase the likelihood of written ACP (Carr, 2012b; Ha & Pai, 2012; Harrison et al., 2016; Kelly et al., 2013; Khosla et al., 2015; Mezey et al., 2000; Moorman & Inoue, 2012; Muni et al., 2011; Rao et al., 2014; Rosnick & Reynolds, 2003; Su, 2008). Net worth, although less-frequently studied, also appears to be positively associated with advance directive completion (Bischoff et al., 2013; Carr, 2012c; Su, 2008). Carr (2012c) found that the effect of net worth on having a living will and/or durable power of attorney was substantially attenuated when having a testamentary will was controlled, suggesting that economic resources may influence written ACP by providing access to legal professionals who can offer information about and assistance with completing advance directives.

**Insurance.** Economic resources may also influence written ACP by facilitating access to health care professionals and higher quality health care. Having private health insurance and paying privately for nursing home care have been found to increase the odds of having an advance directive, whereas having no insurance or relying on Medicaid to pay for medical or



long-term care are associated with lower odds of written ACP (Bradley et al., 1998; Butler et al., 2015; Mezey et al., 2000; Muni et al., 2011; Murphy et al., 1996).

**Need factors.** Need factors are how an individual's health status and conditions motivate engagement in a health behavior.

**Health status.** Some studies suggest that poorer overall health and/or function is associated with greater odds of written ACP (Bischoff et al., 2013; Carr, 2012b; Morrison et al., 1998; Murphy et al., 1996; Rao et al., 2014; Sudore et al., 2008). In qualitative studies, a common reason given for not completing an advance directive is the perception of being too healthy to need one (Cugliari, Miller, & Sobal, 1995; Fried et al., 2016; Schickedanz et al., 2009). Those for whom death was expected are more likely to have completed advance directives than those who died unexpectedly (Khosla et al., 2015; Koss & Baker, 2016). However, a substantial proportion of studies failed to find a significant association between general health status and written ACP (Allen et al., 2003; Bradley et al., 1998; Carr, 2011, 2012c; Carr & Khodyakov, 2007; Huang et al., 2016; Jackson et al., 2009; Moorman & Inoue, 2012; Su, 2008). One recent study using data from the National Health and Aging Trends Study (NHATS) observed that participants who reported being in excellent or very good health had higher probabilities of having advance directives than those in poorer health, although those with one or two chronic medical conditions were more likely to have engaged in written ACP than those with none (Harrison et al., 2016).

**Health conditions.** A few researchers have also tested possible relationships between specific health conditions and ACP. Cancer is associated with higher odds of having an advance directive (Bischoff et al., 2013; Hanson & Rodgman, 1996; Khosla et al., 2015), whereas no significant relationship between written ACP and heart disease has been found (Bischoff et al.,

2013; Butler et al., 2015; Khosla et al., 2015). Khosla and colleagues (2015) observed that HRS participants who died of a respiratory condition were more likely to have a living will, but there was no relationship with appointing a health care proxy. Bischoff and colleagues (2013) observed a negative relationship that approached significance between advance directive completion and having a history of diabetes. A study of patients diagnosed with different terminal illnesses found that having amyotrophic lateral sclerosis (ALS) increased the likelihood of having an advance directive (Ho et al., 2016). Individuals diagnosed with dementia or reporting memory problems have been found to be less likely to have living wills, but equally likely to possess durable powers of attorney (Harrison et al., 2016; Khosla et al., 2015). Differences may be partly explained by variability in the predictability and patterns of disease trajectories as well as the likelihood that the disease has or will impair patients' abilities to make or communicate health care decisions.

### **Summary of Key Findings and Gaps in the Literature**

In summary, public education efforts alone do not appear to directly impact advance directive completion, although information accompanied by ongoing counseling and assistance is more effective. Interactions with health care providers increase the likelihood of completing advance directives. However, the role that providers play in promoting written ACP may be constrained by personal comfort and familiarity with discussing end-of-life issues as well as institutional barriers. Older adults who engage in estate planning with the assistance of attorneys are more likely to complete advance directives. Results from studies on the influence of marital and parental status as well as relationship quality are mixed, while evidence that experiencing the death of a loved one motivates ACP is more robust.

At the individual level, it is difficult to generalize across studies due to differences in sample characteristics, how ACP variables are defined, and what predictor variables are included in the model. There is consistent and strong evidence that older age, higher education, being white, and higher income each increases the odds of having an advance directive. Findings on the influence of gender are mixed, with most studies indicating either a higher likelihood among females or no gender differences. Results are also mixed regarding the relationship between having an advance directive and poorer health. In Table 1, I present results from four recent studies of advance directive completion using different nationally-representative datasets to illustrate these trends and provide an overview of effect sizes of these commonly studied variables.

Other individual-level variables are studied with less frequency or only with relatively small, non-representative samples. Greater wealth appears to increase the likelihood of engaging in ACP. Findings on how religion and religiosity impact advance directive completion do not follow a consistent pattern. Wanting more life-sustaining treatment and death anxiety or avoidance are negatively associated with written ACP. The little data available suggest a positive relationship between advance directive completion and both conscientiousness and agreeableness, but not openness. Multiple studies have found that those with cancer are more likely to have advance directives. Cognitive impairment appears to lower the odds of documenting end-of-life instructions in a living will but is not associated with appointing a health care proxy in a durable power of attorney.

Table 1  
*Results from Four Studies of Advance Directive Completion*

Variable	Rao et al. <sup>a</sup>	Koss & Baker <sup>b</sup>	Huang et al. <sup>c</sup>	Harrison et al. <sup>d</sup>
	OR [95% CI]	OR [95% CI]	OR [95% CI]	PP [95% CI]
Age		1.03 <sup>e</sup> [1.02, 1.04]	1.6 <sup>f</sup> [1.2, 2.0]	
18-34	Reference			
35-54	1.59 [1.34, 1.91]			
55-64	3.27 [2.68, 4.00]			
65+	8.1 [6.63, 9.92]			
65-74				45.4 [40.4, 50.3]
75-84				55.6 [51.0, 60.2]
85+				65.3 [60.4, 70.3]
Gender				
Female	Reference	1.00 [.88, 1.14]	1.4 [1.1, 1.8]	54.2 [50.0, 58.4]
Male	.68 [.60, .77]	Reference	Reference	49.5 [45.3, 53.7]
Race/ethnicity				
White	Reference	Reference	Reference	58.6 [54.9, 62.2]
Black	.69 [.55, .85]	.18 [.12, .27]	.43 [.24, .76]	26.0 [21.1, 30.8]
Hispanic	.77 [.63, .94]		.70 [.42, 1.2]	23.0 [14.7, 31.2]
Other	.73 [.55, .97]		.98 [.46, 2.1]	35.6 [21.3, 50.0]

Table 1 (cont.)

Variable	Rao et al. <sup>a</sup>	Koss & Baker <sup>b</sup>	Huang et al. <sup>c</sup>	Harrison et al. <sup>d</sup>
	OR [95% CI]	OR [95% CI]	OR [95% CI]	PP [95% CI]
Education				
< high school	Reference	Reference	.63 [.36, 1.1]	
High school	1.86 [1.28, 2.76]	1.31 [1.14, 1.52]	Reference	
High school or less				42.2 [38.1, 46.2]
More than high school		2.12 [1.81, 2.49]		62.6 [58.3, 66.7]
Some college	2.21 [1.53, 3.25]		1.7 [1.2, 2.3]	
College	3.21 [2.19, 4.81]		2.2 [1.6, 3.0]	
Post graduate	3.05 [2.06, 4.59]			
Income (\$)				
< 25,000	Reference		Reference <sup>g</sup>	41.8 [37.3, 46.2]
> 25,000	1.22 [1.00, 1.49]			59.4 [55.2, 63.5]
25,000-49,000	1.48 [1.20, 1.82]		1.4 [.98, 2.0]	
50,000-74,999	1.48 [1.20, 1.82]		1.6 [1.1, 2.4]	
75,000+	1.78 [1.48, 2.16]			
75,000-99,999			1.4 [.98, 2.1]	
100,000-125,000			1.6 [1.1, 2.5]	
125,000+			1.5 [1.0, 2.3]	

Table 1 (cont.)

Variable	Rao et al. <sup>a</sup>	Koss & Baker <sup>b</sup>	Huang et al. <sup>c</sup>	Harrison et al. <sup>d</sup>
	OR [95% CI]	OR [95% CI]	OR [95% CI]	PP [95% CI]
Self-rated health				
Excellent				57.0 [52.4, 61.5]
Excellent or very good			Reference	
Good			Reference	48.5 [43.1, 53.8]
Fair or poor			1.1 [.78, 1.5]	47.5 [41.5, 53.5]

*Note.* OR = odds ratio; CI = confidence interval; PP = predicted prevalence (%).

<sup>a</sup> Rao et al. (2014). Data source: 2009 and 2010 HealthStyles Survey. ORs also adjusted for presence of chronic disease, regular source of health care, and end-of-life concerns.

<sup>b</sup> Koss & Baker (2016). Data source: 2002-2012 Health and Retirement Study exit surveys. ORs also adjusted for year of death, marital status, residence in long-term care facility, geographic region, and whether death was expected.

<sup>c</sup> Huang et al. (2016). Data source: 2013 GfK KnowledgePanel internet survey. ORs also adjusted for marital status, employment status, geographic region, residence in metropolitan area, internet access, religious attendance, religious affiliation, and health care attitudes and preferences.

<sup>d</sup> Harrison et al. (2016). Data source: 2012 National Health and Aging Trends Survey. PPs only adjusted for age, sex, and race/ethnicity.

<sup>e</sup> Age measured in years.

<sup>f</sup> Age measured in decades.

<sup>g</sup> Huang et al., reported only unadjusted odds for income.

This research provides much information about the individual factors associated with advance directive completion, but relatively little about contextual factors or processes. We still do not know how the characteristics and experiences associated with one's own ACP – e.g., age, education, health, or hospitalization – may influence the ACP of others such as spouses, parents, or adult children, and vice versa. Only a few studies have considered ACP in the context of marriage. When ACP is studied in the marital context, the outcome variable is almost always limited to the advance directive completion of only one of the two spouses. Moorman and colleagues (2014; 2012) controlled for the lack of independence of their couple data but did not model the potential interdependence of partners' ACP. As yet no published study has modeled or

explored, either quantitatively or qualitatively, advance directive completion by older husbands and wives as a dyadic or interdependent process. It is this gap in the literature that the present research project will begin to address.

## **Chapter 3**

### **Individual and Relational Decision Making**

As the literature review in Chapter 2 shows, much of the research on advance directive completion has focused on individual factors. This may be in part because available data are often collected only at the individual level. There are also historical reasons for the emphasis on the individual and the neglect of social context that I discuss in more detail in this chapter. I then present several critiques of this individualistic perspective and arguments for why advance directive completion by older married adults should be understood as an interdependent process. I end the chapter by describing alternative relational theoretical frameworks and propose a relational model of ACP by older couples that incorporates aspects of these frameworks into the transtheoretical model of behavioral change (TTM).

#### **Development of Advance Directives**

Advance directives (originally called living wills) developed in the United States during the 1960s in response to three interrelated trends in health care (Brown, 2003). First, advances in life-sustaining technologies enabled increasing numbers of patients to survive what were once fatal conditions or traumas. Second, advocacy efforts promoting patients' rights led to a shift away from a medical culture dominated by benevolent paternalism and toward placing more emphasis on patient autonomy and control. Third, growing interest in death and dying – as manifested in the hospice movement for example – raised public awareness of pain management, dignity, and other quality of death issues.

Advance directives emerged out of the field of bioethics as one of several responses to these changes in modern medicine (Fox, 1990). Initially focused on ethical human research and informed consent, bioethicists soon began advocating for the recognition of the right to refuse



treatment, first contemporaneously with and then in advance of a life-threatening medical condition. A series of legal cases involving petitions to withdraw life-sustaining treatment filed by family members of incapacitated patients culminated in the United States Supreme Court case *Cruzan v. Director, Missouri Department of Health* (1990). The Court recognized a constitutional right to refuse life-sustaining treatment in advance of medical need. However, the Court also allowed states to require clear and convincing evidence of such wishes in order to override the default of preserving life. In response to this litigation and public pressure, state legislatures gradually approved statutory advance directive forms to provide clear and convincing evidence of medical care preferences as well as to appoint health care proxies to carry out these instructions (Brown, 2003).

This early focus on rights led to individual autonomy becoming the dominant principle underlying ACP and bioethics more broadly. One consequence of the emphasis on individualism is that sociological theories of family and community have been largely absent from bioethical discourse on medical decision making (Fox, 1990). The focus has been almost exclusively on the exercise of individual autonomy, conceived as an internal, rational process of weighing the pros and cons of various options in light of personal goals and values. Others are viewed as either irrelevant or potentially threatening to the exercise of autonomy. Beauchamp and Childress, in *Principles of Biomedical Ethics* (1994), defined autonomy as, “personal rule of the self that is free from both controlling interferences by others and from personal limitations that prevent meaningful choice” (p. 121).

### **Critiques of Individual Autonomy**

Critics point out that, by neglecting familial or collective decision making as well as the social contexts in which decisions are made, the dominant biomedical framework fails to reflect

the lived experiences and viewpoints of many patients (Baker, 2002; Ikonomidis & Singer, 1999; Werth et al., 2002; Winzelberg, Hanson, & Tulskey, 2005). Fox (1990) offered this general critique of the biomedical emphasis on individual autonomy:

The weight that bioethics has placed on individualism has relegated more socially-oriented values and ethical questions to a secondary status. The concept and the language of *rights* prevails over those of *responsibility*, *obligation*, and *duty* in bioethical discourse. The skein of relationships of which the individual is a part, the socio-moral importance of the interdependence of persons, and of reciprocity, solidarity, and community between them, have been overshadowed by the insistence on the autonomy of self as the highest moral good. Social and cultural factors have been primarily seen as external constraints that limit individuals. They are rarely viewed as forces that exist *inside*, as well as outside of individuals, shaping their personhood and enriching their humanity (p. 207).

There is increasing awareness of the disconnect between the dominant bioethical definition of autonomy and how end-of-life decision making is actually carried out. Such decisions frequently have consequences for family and are often the result of consultative or joint processes (Haley et al., 2002; Moorman, 2010; Rettig, 1993). Although control over medical care at the end of life is valued by older participants, many engage in ACP to relieve loved ones of the responsibility for making difficult decisions, to avoid conflict among family members, and/or to reduce the burdens of caregiving as well as the potential emotional and financial costs of end-of-life medical care (Doukas & Hardwig, 2003; Fried et al., 2009; Levi et al., 2010; Malcomson & Bisbee, 2009; McPherson et al., 2007; Medvene et al., 2007, 2002; Phipps et al., 2003; Rosenfeld, Wenger, & Kagawa-Singer, 2000).

Not all family involvement is positive. Reliance on informal family decision making may lead some to view formal ACP as unnecessary (Fried et al., 2009; Morrison et al., 1998). Those who meet with resistance from family members when broaching the subject of end-of-life care may be discouraged from proceeding with ACP (Fried et al., 2009; Malcomson & Bisbee, 2009; Singer et al., 1998). The lack of availability or willingness of a family member to serve as a

health care proxy can hinder durable power of attorney completion (Fried et al., 2009; Morrison et al., 1998). Family members' cooperation may be particularly important for individuals with dementia or other debilitating conditions that prevent them from completing advance directives without assistance (Jethwa & Onalaja, 2015).

### **Why Study ACP by Married Older Adults as an Interdependent Process?**

The majority of older people are married during at least a portion of their later years (Administration on Aging Administration for Community Living, U.S. Department of Health and Human Services, 2014). For those who are married, life events take place in the context of marital histories and patterns of behavior (Curl & Townsend, 2014). "Marriage creates a world of shared meaning and experience from which it is difficult to disengage" (Walker et al., 2009, p. 455). From health to finances, marriage affects almost every facet of aging (Waite et al., 2015). The marital relationship becomes even more central in later life as social circles narrow due to transitions away from employment and parenthood roles, the loss of friends to illness, death, or relocation, or a growing preference to spend more time with intimate partners as an emotion regulation strategy (Hoppman & Gerstorf, 2009; Landis, Peter-Wight, Martin, & Bodenmann, 2013).

One spouse may exert influence on the other spouse's ACP through his or her personal attributes or experiences. These are referred to as partner or spillover effects (Bourassa, Memel, Woolverton, & Sbarra, 2015; Kenny et al., 2006). For example, a spouse who displays a high level of conscientiousness may be more likely to both complete an advance directive and encourage a spouse to do so as well. A significant event in the life of one spouse, such as making end-of-life decisions for a parent, may motivate both spouses to engage in their own end-of-life planning.

Married partners often jointly experience events and conditions that can make ACP seem more relevant or urgent, what are called common fate effects (Kenny et al., 2006). Moving to a new home is a typical example of a common fate occurrence. Even when an event or circumstance directly occurs to only one person, such as a cancer diagnosis, couples may experience it as a common fate event with consequences for both partners. Spouses may then engage in dyadic or collaborative coping (Bodenmann, 2005). Dyadic coping goes beyond social support to encompass the pooling of shared resources and joint problem solving (Berg et al., 2008). Problems as well as the responsibility for addressing them are perceived as being shared rather than belonging to one partner alone (Moorman, 2010). When engaged in dyadic coping, spouses may use collective selective optimization with compensation to help one another to prioritize goals, play off of one another's strengths, and find ways to work together to minimize the impact of limitations or losses (Baltes & Carstensen, 1999; Hoppmann & Gerstorf, 2009, 2016). This collaboration may lead spouses to encourage and support one another to engage in ACP as a joint response to a common challenge. However, dyadic coping is not always adaptive and can result in one spouse hampering the other's development and adjustment (Hoppmann & Gerstorf, 2009). Those not willing or able to engage in ACP alone may therefore be hindered by their partner's reluctance or inability.

Partner and common fate effects frequently differ by gender. With a few exceptions, research has shown that women tend to be more sensitive to both the quality of their marriages and the physical, cognitive, and emotional states of their spouses (Berg & Upchurch, 2007; Carr, Freedman, Cornman, & Schwarz, 2014). Older women may be more affected by or sensitive to their partners' status due to societal expectations that wives play caregiving roles as well as cultural norms that result in women assuming relational self-concepts (Bourassa et al., 2015).

The cultural associations of autonomy with masculinity and interpersonal relationships with femininity may be protective for men while making women particularly vulnerable to the negative effects of poor marital relationships or spouses' health problems (Walker & Luszcz, 2009). However, gender roles and norms have undergone a radical transformation in the past decades. Feminism and women's entry into the work force on a large scale transformed gender and spousal roles and expectations. As the dualistic associations of autonomy and self-sufficiency with masculinity and caring and interpersonal relationships with femininity continue to blur, it is likely that these gender differences in spousal influence will attenuate (Berg & Upchurch, 2007).

### **A Relational Model of Written ACP by Married Adults**

As discussed in Chapter 1, the transtheoretical model of behavioral change (TTM) has been used to illustrate the process of engaging in ACP. The TTM defines behavioral change as a series of steps from Precontemplation to Maintenance motivated by a shifting perception of the relative advantages and disadvantages of adopting a new behavior (Prochaska et al., 1994). Although it recognizes that this decisional balance includes consideration of the interests and judgments of others, it is still essentially a model of individual decision making and change. I propose an expansion of the TTM to reflect more comprehensively the relational aspects of health behavioral change – specifically advance directive completion – by older married adults (Figure 1).

One element missing from the TTM is the social context in which the skills needed to exercise autonomy are developed and in which ACP takes place. Two theoretical orientations are useful for considering how to incorporate social context into the TTM. Relational autonomy, which emerged out of feminist scholarship, asserts that autonomy requires skills that must be

learned and practiced through socialization and that our preferences, goals, and values are shaped by the social world in which we are immersed (Barclay, 2000). The biopsychosocial or ecological model nests the individual like a *matryoshka* doll inside a hierarchy of increasingly larger units starting with the family and working outward to the community, organizations, and society (Leichtentritt & Rettig, 2001; McLeroy, Bibeau, Steckler, & Glanz, 1988; Rettig, 1993; Schmid, Allen, Haley, & DeCoster, 2009). Individuals' health decisions and behaviors are shaped by and carried out in these contextual layers. To reflect this social context in which skills necessary to exercise autonomy are developed and within which decisions are made, I place the TTM stages in the center of concentric circles representing personal characteristics, spousal characteristics, interpersonal relationships, interactions with organizations such as hospitals and other health care providers, and policies. Older adults operate in and are influenced by all of these contexts as they move toward and through engagement in ACP. Spouses occupy distinct but overlapping interpersonal and organizational contexts while operating in the same policy context.

A second element lacking in the TTM is interdependence, or the recognition that spouses' passages through the stages of change may be mutually influential. Elder and Shanahan (2006) argue that older adults live linked lives across intertwined life courses. People who lead linked lives share patterns of behavior, attitudes, and perceptions that influence their own and one another's conduct and outcomes (Bourassa, Memel, Woolverton, & Sbarra, 2015; Curl & Townsend, 2014; Lewis et al., 2006). The behavioral change of one spouse may be influenced by or at times even dependent on the other spouse also adopting that behavior. In the proposed model, intertwining arrows represent the interdependence of husbands' and wives' passages from one stage of change to the next.

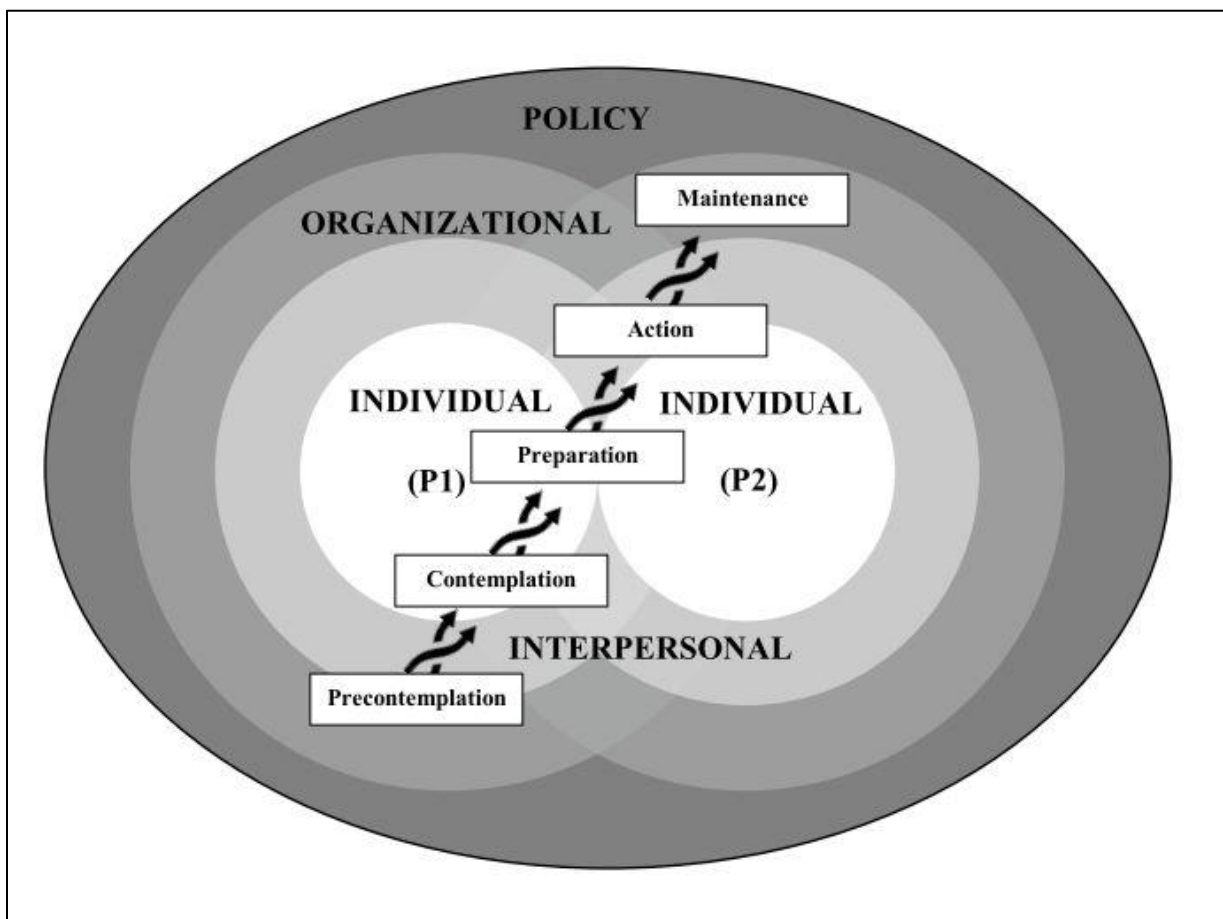


Figure 1. Proposed relational transtheoretical model of behavioral change (TTM). Adapted from Prochaska et al. (1994).

### Why a Mixed Methods Research Design?

I tested the accuracy and usefulness of the proposed relational TTM by conducting two complementary studies of advance directive completion by older married adults. With quantitative dyadic data, I examined relationships between advance directive completion and both personal and spousal factors. These factors included both individual- and organizational context-level variables. The individual-level factors were age, education, and self-reported health status. The organizational-context variables were two measures of interactions with health care providers, namely having a regular source of health care and prior hospitalization or outpatient

surgery. I also interviewed married older adults who had engaged in end-of-life planning. Through these interviews, I was able to assess whether participants' descriptions of the events leading up to their ACP corresponded to the process depicted in the proposed relational model. In addition, I observed to what extent they described their processes as independent of or interdependent with their spouses' processes.

Mixed methods studies involve the concurrent or sequential collection and/or analysis of both quantitative and qualitative data (Creswell, Clark, Gutmann, & Hanson, 2003). The use of multiple methods can enable the researcher to gain a more complete understanding of a complex human behavior or experience (Morse, 2003). Here, the quantitative data allowed me to test for associations between advance directive completion and personal, spousal, and contextual factors that are represented in the proposed relational TTM as concentric and overlapping circles (contextual interdependence). However, the lack of information regarding when or why participants engaged in ACP made it impossible to evaluate all aspects of the model with quantitative data alone. The qualitative data permitted me to examine the process elements of the proposed relational TTM represented by the boxes linked by intertwined arrows (process interdependence).

Mixed methods research designs differ in terms of emphasis on qualitative or quantitative methodology, whether they are primarily exploratory or explanatory, in what order the qualitative and quantitative data are collected and analyzed, and at what stage the quantitative and qualitative elements are integrated. I used a sequential explanatory design (Creswell et al., 2003) which first entailed analyzing quantitative data followed by the collection and analysis of qualitative data. This is consistent with what Morse (2003, p. 190) refers to as a "methodological triangulated design" in that, although the sub-projects in combination contribute to a broader



programmatic research goal, each adheres to its own assumptions and standards appropriate for the methods used and could stand alone. My approach was primarily, but not entirely, explanatory in that I began with a set of predictions and a proposed theoretical model to test with the data. The quantitative and qualitative data were analyzed separately and then integrated in the interpretation phase of the study.

## **Chapter 4**

### **Quantitative Study: Methods**

The main research question of the quantitative study was to what extent are personal and spousal factors associated with advance directive completion by older married adults. I predicted that the personal characteristics of older age, higher education, and poorer general health as measured by self-reported health status would be associated with a greater probability of having an advance directive. The organizational-level factors of hospitalization and/or outpatient surgery in the past ten years and having a regular place where one receives medical care were also anticipated to be associated with a higher likelihood of advance directive completion.

Each of these relationships has been demonstrated in prior research. Age may be positively associated with ACP because planning for the end of life becomes more relevant as one approaches one's own death and experiences the illnesses and deaths of others. Similarly, those in poorer health may be motivated to complete advance directives by a heightened awareness of their own vulnerability or mortality. Education is correlated with health literacy, which may increase individuals' awareness of ACP, and economic status, which may provide the opportunity to engage in ACP along with estate planning. At the time of admission, patients going into the hospital or undergoing outpatient surgery are provided information about advance directives which may increase the likelihood that they engage in written ACP. The underlying health conditions triggering admission may also motivate some to plan for incapacity or the end of life. Finally, a regular health care provider may raise the issue of ACP with patients and assist those who desire to complete advance directives.

In addition to being associated with one's own likelihood of having an advance directive, I predicted that these variables would operate in a similar manner on spouses' probabilities of

advance directive completion. Specifically, I anticipated that one spouse's age, education, poorer overall health, and engagement with health care providers would be positively associated with the other spouse's likelihood of having an advance directive. Those with spouses who are significantly older or sicker may engage in ACP sooner than they would have otherwise because their spouses are likely to be more motivated to complete advance directives and to encourage their younger or healthier spouses to do so as well. A spouse who is more highly educated or who received information about ACP from a health care provider may share information about advance directives with a less-educated spouse or one who does not have an ongoing relationship with a doctor. The hospitalization or outpatient surgery of one spouse may trigger both spouses to complete advance directive forms together.

A secondary research question was to what extent do actor and partner effects differ by gender. Husbands, being on average several years older than their spouses (England & McClintock, 2009), are more likely to experience age-related health issues before their wives do. To the extent that husbands and wives complete advance directives in response to husbands' health events, no change in advance directive status should occur for either spouse when a wife subsequently experiences her own health issues. Women may also be more likely to interpret spousal health events as requiring a joint response (Lewis et. al, 2006). Therefore, I expected to find stronger relationships between men's hospitalization/outpatient surgery and health status and both their own and their spouses' probabilities of having an advance directive.

### **Non-independence and the Actor-Partner Interdependence Model**

The main challenge (and opportunity) of quantitative dyadic data is the lack of independence. Many commonly used statistical methods assume that the value of one

observation does not influence the values of the other observations. This assumption is violated with dyadic data because of the linkages between the respondents.

Kenny and colleagues (2006) identify four potential sources of non-independence in dyadic data. Dyads may have originally been united based on shared characteristics, what they call *compositional effects*. For example, through assortative mating individuals choose marital partners who are similar to themselves. *Partner effects* occur when the attributes or behaviors of one dyad member influence the other. For example, when one spouse stops driving, the driving habits of the other spouse will likely be affected. Dyad members' simultaneous influence on one another is referred to as *mutual influence*. For example, the communication styles of each spouse may influence the other's marital satisfaction. Finally, *common fate effects* occur when dyad members experience the same condition, such as shared housing. Because of these potential sources of non-independence, husbands and wives in the same sample are likely to be more similar to one another than to others in the sample.

To address the lack of independence in marital dyadic data, researchers may choose to uncouple the data by either retaining data for only one randomly selected spouse from each couple or, when data are limited to heterosexual couples, by analyzing men and women separately. Both of these approaches are suboptimal because they halve the sample size, resulting in substantial loss of power. The first approach does not allow for any analysis of couple effects and the second does not allow for the analysis of mutual effects (Kenny et al., 2006). Two recommended methods of analyzing dyadic data are multilevel modeling (MLM) and structural equation modeling (SEM) or path analysis. MLM adjusts for non-independence by estimating random intercepts (Kenny et al., 2006). The effect of each variable in the model is assumed to be uniform across dyads because, unlike larger clusters, there is not enough information to calculate

separate slopes. However, each dyad is permitted to start from a different baseline (Spain, Jackson, & Edmonds, 2012). SEM or path analysis accounts for non-independence by allowing predictor variables to freely covary and by estimating the covariance between latent residuals (Peugh, David DiLillo, & Jillian Panuzio, 2013). SEM is a more flexible method, allowing for model fit assessment and complex error structuring, although both SEM and MLM should yield similar results (Wendorf, 2002).

The potential interdependence of advance directive completion by the older married couples in this sample was examined using path analysis and the Actor-Partner Interdependence Model (APIM) (Kenny et al., 2006). APIM enables the researcher to estimate actor and partner effects of and on dyad members simultaneously. An actor effect is how one person's predictor is related to that person's outcome. A partner effect is how one person's predictor is related to the other person's outcome. To account for the non-independence of the data, the predictor variables are allowed to covary and the covariance of residuals is estimated.

Figure 2 illustrates the paths of these potential effects.  $X_1$  and  $Y_1$  are the predictor and outcome variables for Dyad Member 1, and  $X_2$  and  $Y_2$  are the predictor and outcome variables for Dyad Member 2. Lines labeled "a" indicate actor effects and lines labeled "p" are partner effects.

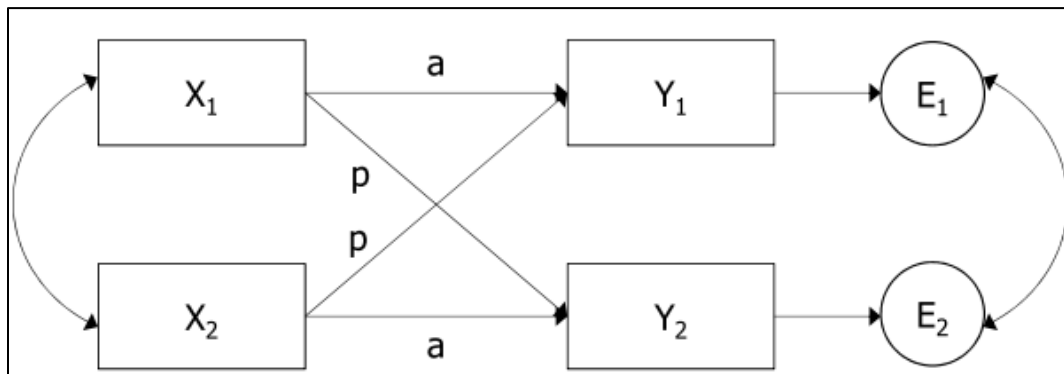


Figure 2. Actor-Partner Interdependence Model (APIM). Adapted from Kenny et al. (2006).

## **Data**

Data were obtained from the Health and Retirement Study (HRS), a nationally-representative longitudinal survey of U.S. adults over the age of 50 and their spouses administered by the University of Michigan. A new cohort is added every six years based on a multi-stage probability design involving geographic stratification and clustering. The HRS has a high response rate both at baseline and follow-up. Initial response rates range from approximately 70-80%, and increase to 85-93% in subsequent follow-up waves. Certain demographic groups are purposefully oversampled, including African Americans and Hispanics (Sonnega et al., 2014).

Once a person enrolls in the study, his or her spouse (if married) is also invited to participate in the HRS regardless of age. As a result, some participants are younger than 51 when they enter the study. The subsequent dissolution of a marriage by death or divorce does not affect enrollment, and one or both former spouses may continue to participate in subsequent surveys. Upon remarriage, the new spouse may enroll in the study (Sonnega et al., 2014).

Data are collected primarily through interviews, either in-person or by telephone. Most interviews with new enrollees are conducted face-to-face. Since 2006, the sample has been randomly divided into two groups with which in-person and telephone interviews are conducted in alternate waves so that each participant is interviewed in person every four years. Those with whom in-person interviews are conducted are also asked to allow physical and biological measures to be collected and to complete a psychosocial questionnaire (Sonnega et al., 2014).

The core interviews cover a broad range of topics including demographics, health, cognition, family structure and financial transfers, functional limitations, housing, employment and retirement, health service utilization and insurance, assets and income, and marital history.

The supplemental psychosocial questionnaire includes questions about life circumstances, well-being, social relationships, and personality. When a participant dies, a proxy is asked to complete an exit interview about the events leading up to and after death, including end-of-life medical care and expenditures, family interactions, and estate disposition (Sonnega et al., 2014).

Until 2012, information about ACP was collected only through exit interviews by asking proxy respondents whether deceased participants had discussed medical care preferences or completed living wills and/or durable powers of attorney for health care prior to death. In 2012, several ACP questions were added to the core interview and asked of all participants age 65 and older. Although this is an improvement over proxy reporting, an important limitation to acknowledge is that the 2012 HRS asked about participants' current advance directive status but did not collect information about when the forms were completed. Therefore, conclusions are limited to identifying the correlative associations between independent variables and advance directive completion.

Raw data are made available by the University of Michigan via its website (<http://hrsonline.isr.umich.edu>). In addition, the RAND Center for the Study of Aging produces a user-friendly version of a subset of the HRS data called a "fat file." This file contains cleaned and processed variables for both individuals and spouses. RAND combines data across waves and performs imputations to derive some aggregate values, such as total household income or assets (Chien et al., 2014). I obtained data from the RAND fat file, if available, and then merged HRS raw data for unavailable variables with the RAND data.

**Sample.** To be included, data from both spouses (all heterosexual married couples) must have been collected in the 2012 HRS wave. To ensure stability of dyads across the waves drawn upon for this study (2004-2012), only couples who had been married for at least ten years were

included in the sample. Because information about when advance directives were completed was not available, the marital duration requirement increased the chances that any written ACP participants engaged in was done while they were married to their current spouses. There may also be significant differences in how long-married couples influence one another's ACP compared to recently-married older couples, so the ten-year duration requirement mitigated this potential confounding effect. Because I wanted to study how the advance directive completion of husbands and wives may be shaped by overlapping and shared social contexts, couples were also excluded if one or both spouses lived in a nursing home. Questions about advance directives were asked only of participants 65 and older, so couples were dropped if either spouse was younger than 65 at the time of the 2012 interview.

There were 20,554 participants in the HRS in 2012. Approximately half (11,753) were married. Of these, data were collected from both spouses for 5,659 married couples. A total of 4,963 of these couples had been married for at least 10 years (696 excluded for being married less than 10 years). After dropping 2,678 couples with one or both spouses under 65 years of age and 42 couples with one or both spouses living in nursing homes, the final sample was made up of 2,243 heterosexual married couples. The sample included participants from the original HRS sub-sample (born 1931-1941) who entered the study in 1992, the AHEAD sub-sample (born 1923 or earlier) who entered the study in 1993, the War Baby sub-sample (born 1942-1947) who entered the study in 1998, and the Children of the Depression sub-sample (born 1924-1930) who entered the study in 1998 (Sonnega et al., 2014).

**Data management.** Dyadic data analysis requires different data structuring depending on whether dyads are distinguishable or indistinguishable as well as what statistical method is employed. Members of distinguishable dyads can be differentiated by a meaningful attribute,



whereas dyads are indistinguishable when there is no trait relevant to the study on which to differentiate one from the other (Kenny et al., 2006). Because heterosexual spouses are distinguishable by gender and path analysis was used, I organized the data in a dyad structure with one row per dyad and two columns per variable (one for each dyad member).

All variables used in the study were measured at the respondent level and made available in multiple files linked by respondent-level, household-level, and couple-level identifiers. A unified file was created by merging all sub-files by respondent-level identifiers, arranged in an individual structure with one row for each participant (two rows per married couple). This file was then converted to a dyad structure by first dividing the file by gender, renaming the variables, and then merging the men-only and women-only files using household and couple identifiers.

**Weights.** The complex sampling design of the HRS makes the use of sampling weights necessary to derive population inferences (Sonnegga et al., 2014). However, sampling weights are less important when data are used to test relationships among variables. Individual weights are particularly difficult to use when analyzing data that is structured dyadically because it is unclear which dyad member's weight should apply. I therefore conducted all analyses using unweighted data. Other researchers analyzing HRS data dyadically have also elected to forgo the use of sampling weights (Ayotte, Yang, & Jones, 2010; Townsend, Miller, & Guo, 2001). However, population inferences cannot be made based on the findings of this study.

**Missing data.** Missingness was examined using STATA 14 (StataCorp, 2015). When outcome variables are categorical, multiple imputation is the recommended method for handling missing data (Brown, 2015). Unfortunately, Mplus version 7 (Muthén & Muthén, 2015) (the statistical software package I used to conduct path analyses) does not permit the DIFFTEST

function to be run on multiple imputed datasets. As described in the Analysis section of this chapter, the DIFFTEST function must be used to calculate adjusted  $\chi^2$  difference *p*-values appropriate for nested models with categorical outcome variables (Brown, 2015). Due to this software limitation, models were initially estimated on a single dataset using listwise deletion to handle missing data. This resulted in 108 dyads (5%) being dropped from the path analyses because of missing data on one or more variables, bringing the sample size to 2,135 couples for multivariate analyses.

To evaluate the effect that missing data may have had on the estimates, I imputed 100 datasets using all of the variables in the models as well as race/ethnicity as an auxiliary variable. All models were rerun using multiple imputation and visually compared to the models estimated with one dataset.

## **Measures**

The outcome variables were husbands' and wives' advance directive completion. Predictor variables were education, age, self-reported health status, hospitalization and/or outpatient surgery in the past 10 years, and having a regular health care provider other than the emergency room. These variables were initially chosen based on prior research indicating significant associations with written ACP and retained following bivariate analyses.

Race/ethnicity was used as an auxiliary variable for multiple imputation and is reported descriptively, but it was not included as a predictor in the models. Preliminary review of the data revealed that only 4% of spouses were of different race or ethnic groups. This high degree of agreement would make it impossible to distinguish actor and partner effects and would cause multicollinearity problems.

**Advance directive status.** The advance directive dichotomous variable was constructed by combining responses to two questions asked in 2012:

1. “Have you made any legal arrangements for a specific person or persons to make decisions about your care or medical treatment if you can not make those decisions yourself? This is sometimes called a ‘Durable Power of Attorney for Health Care.’”
2. “Have you provided written instructions about the care or medical treatment that you want to receive if you can not make those decisions yourself? This is sometimes called a ‘Living Will.’”

The combination of these variables is consistent with the PSDA’s definition of an advance directive as a written instruction, such as a durable power of attorney or living will, recognized under state law. Participants who responded positively to either or both of these questions were coded as having an advance directive. Respondents were classified as not having an advance directive if they responded negatively to both questions. Those who were missing data for one question and either responded negatively or failed to respond to the other question were coded as missing (see Table 2).

Table 2  
*Crosstab of Living Will and Durable Power of Attorney Responses (n = 4,486)*

Durable power of attorney	Living will			Total
	Yes	No	Missing	
Yes	1,722	339	19	2,080
No	405	1,942	11	2,358
Missing	19	8	21	48
Total	2,146	2,289	51	4,486

*Note.* Light shaded cells coded as possessing an advance directive; dark shaded cells coded as not possessing an advance directive; unshaded cells coded as missing.

**Education.** The RAND fat file contains an education variable with the following categories: less than high school, high school diploma, GED, some college, and college degree or higher. For this study, the categories high school diploma and GED were collapsed into one

level. Education was treated as an ordinal variable with values ranging from 1 (*less than high school*) to 4 (*college degree or higher*).

**Age.** Age was a continuous variable based on the age (in years) of each respondent at the time of the 2012 interview.

**Self-reported health status.** Self-reported health status was an ordinal variable based on the following question asked in 2012: “Would you say your health is excellent, very good, good, fair, or poor?” Responses were coded using a five-point scale ranging from 1 (*excellent*) to 5 (*poor*). This ordering was retained so that higher values indicated worse self-reported health.

**Hospitalization and/or outpatient surgery in prior 10 years.** The dichotomous variable of whether a person had, in the past 10 years, spent at least one night as a patient in a hospital and/or had outpatient surgery was constructed based on participants’ responses in 2004, 2006, 2008, 2010, and 2012 to the following questions (asked using identical wording across waves):

1. “[Since [Respondent’s last interview]/In the last two years], have you been a patient in a hospital overnight?”
2. “[Not counting overnight hospital stays,)] [Since [Respondent’s last interview]/In the last two years], have you had outpatient surgery?”

Participants were coded as having been hospitalized and/or having undergone outpatient surgery if they responded positively to either question in any wave. Those who responded negatively to both questions in all waves were coded as not experiencing a hospitalization or outpatient surgery in the prior 10 years. Participants who never responded positively to these questions and were missing data in any of the waves were coded as missing. Hospitalization and

outpatient surgery were combined into one variable because both events trigger similar mandatory patient education about advance directives under the PSDA.

**Regular health care provider.** The dichotomous variable of whether a person had a regular place where he or she obtained health care other than an emergency room was constructed by combining responses to two questions asked in 2012:

1. “Is there a place that you usually go to when you are sick or need advice about your health?”
2. “What kind of place [is it/do you go to most often] - a clinic, doctor's office, emergency room, or some other place?”

Only those who responded affirmatively to the first question or who volunteered the answer that they had more than one regular place they went for health care were asked the second question. Participants were coded as having a regular health care provider if they responded affirmatively to the first question (or volunteered that they had more than one place) and did not list the emergency room as the place they used. Participants were coded as not having a regular health care provider if they responded negatively to the first question. Participants who responded affirmatively to the first question but then listed the emergency room as their regular source of health care were also coded as not having a regular health care provider. Cases were coded as missing if the participants failed to answer to the first question or responded affirmatively to the first question but failed to answer the second question.

**Race.** The nominal auxiliary race variable was constructed based on two values generated by RAND. RAND classifies HRS participants into the categories Caucasian, African American, and Other, and also divides them by Hispanic and Non-Hispanic. These two variables were combined to create one variable with four categories: Non-Hispanic White, Non-Hispanic

African American, Non-Hispanic Other, and Hispanic. Any person who responded affirmatively to the Hispanic question was classified Hispanic. Those who responded negatively to the Hispanic question and identified a race were assigned to that race. Respondents who were missing data for the Hispanic question or who responded negatively to the Hispanic question and lacked data on the race variable were coded as missing.

## **Analysis**

**Tests of non-independence.** Independence – that each observation is unrelated to other observations – is a fundamental assumption of probability theory. Since spouses are likely to be more similar to one another than to non-spouses in the sample, tests for non-independence were run in STATA version 14 (StataCorp, 2015) to determine if adjustments needed to be made to account for dyadic covariance. Dyadic non-independence of continuous variables was examined by calculating the correlations between dyad members' values using the Pearson product-moment correlation coefficient (Kenny et al., 2006). Correlation coefficients of .5 and above or -.5 and below indicate a high degree of non-independence. Cohen's kappa was used to test for non-independence of categorical and ordinal variables. This statistic adjusts for agreement expected by chance and, like the Pearson correlation, uses a -1 to 1 scale. Kappa values greater than zero indicate more agreement than would be expected by chance (up to 1 indicating perfect agreement). Values close to zero indicate that agreement is no more than what would be expected by chance. Values less than zero indicate less agreement than would be expected by chance (Kenny et al., 2006).

**Descriptive statistics.** All descriptive analyses were performed in STATA version 14 (StataCorp, 2015). Basic descriptive statistics were generated for all variables included in the models as well as race/ethnicity. Gender differences were examined using the paired sample t-

test for continuous variables, the generalized McNemar's test (or asymptotic symmetry test) for non-ordered categorical variables, and the Wilcoxon signed-rank test for ordinal variables. These tests take into account the within-dyad correlations often present in paired data (Agresti, 1996; Kenny et al., 2006). Bivariate relationships between the advance directive status of husbands and wives and each independent variable were examined using simple logistic regression.

**Path analyses.** The actor and partner effects of the predictor variables on advance directive completion by husbands and wives were modeled using path analysis in Mplus version 7 with robust weighted least squares estimation (WLSMV) (Brown, 2015; Muthén, Muthén, & Asparouhov, 2015). WLSMV was selected for several reasons. First, it is required to accurately compare nested models with non-continuous outcome variables using the adjusted  $\chi^2$  difference test generated by the DIFFTEST function. Second, this estimation method produces model fit indices. Third, it is compatible with theta parameterization which is superior to delta parameterization when residuals are of interest (Brown, 2015) and was recommended on the discussion section of the Mplus website for modeling an APIM with categorical outcome variables (Muthén, 2013).

One disadvantage is that WLSMV employs a probit link function, making coefficients more difficult to interpret than those generated by a logit link function. To interpret the effect of predictor  $x_1$ , one would say that a one-unit increase in  $x_1$  leads to a  $b_1$  change in the z-score of  $Y$ , with  $Y$  being the probability that the binary outcome variable is equal to 1. When model fit is good, probit and logistic regression models should provide similar data fits and statistical significance levels, although the magnitude of the parameter estimates will be about 1.8 times larger in logistic models due to scale differences (Agresti, 1996).

Lack of independence of the predictors was accounted for by allowing exogenous variables to freely covary. When outcome variables are continuous, the APIM calls for estimation of the residual covariance. However, with dichotomous outcome variables, no residual errors are estimated. Instead, I defined a latent factor loaded on the two outcome variables which estimated the marginal covariance between husbands' and wives' probabilities of advance directive completion. This approach was recommended in the discussion section of the Mplus website (Muthén, 2013). By constraining the two factor loadings to be equivalent and fixing the factor variance to equal one, the latent factor was just-identified.

***Global testing of actor and partner effects.*** I fit a series of four nested path models consistent with the multi-step process for testing an APIM outlined by Kenny et al. (2006). These comparisons of nested models were designed to answer two questions. First, did the addition of partner effects significantly improve the overall model? I was interested in whether, as a whole, the APIM was a better approach to modeling advance directive completion than the more common method of estimating only actor effects. Second, were the actor and/or partner effects equivalent for husbands and wives? Here my interest was whether gender differences needed to be taken into account when estimating either the actor model or the APIM. The focus of this stage of the analysis was on relative overall model fit rather than specific coefficients within the models. Table 3 summarizes the different models and comparisons made.

When outcome variables are continuous, nested models may be compared by subtracting the  $\chi^2$  of the more constrained model from the  $\chi^2$  of the less constrained model. This difference has a  $\chi^2$  distribution with degrees of freedom equal to the difference in degrees of freedom between the two models. However, when outcome variables are categorical, the  $\chi^2$  difference does not have a  $\chi^2$  distribution (Brown, 2015). Mplus provides a two-step procedure to calculate



an adjusted  $\chi^2$  difference  $p$ -value appropriate for categorical analysis using the DIFFTEST function (Muthén & Muthén, 1998-2015).

Table 3  
*Actor and Actor-Partner Models and Model Comparisons*

Model	Compared To	Test
<b>1 – Actor Model</b>	none	Estimate actor effects
<b>2 – Constrained Actor Model</b>	Model 1	Global test of gender differences in actor effects
<b>3 – Actor-Partner Model</b>	Model 2	Determine if partner effects are significant
<b>4 – Constrained Actor-Partner Model</b>	Model 3	Global test of gender differences in partner effects

The first step was to estimate an actor model against which the actor-partner model could be compared. If the actor effects are similar for men and women, the path coefficients can be constrained to be equal across genders without negatively impacting model fit. These constraints allow fewer parameters to be estimated, increasing degrees of freedom and power. For example, if the actor effect of age is estimated separately for each gender, then two degrees of freedom are used (one for men's age on men's advance directive completion and one for women's age on women's advance directive completion). However, if these parameter estimates are constrained to be equal, only one degree of freedom is used because the same coefficient estimate represents the relationships between age and both men's and women's advance directive completion.

If the effects are similar for men and women, then the coefficients estimated under the constraint conditions will not be significantly different from the coefficients estimated without the constraints. In that case, the constrained model and the unconstrained model should fit the observed data with approximately the same level of accuracy. On the other hand, if there are significant gender differences in the actor effects, then the coefficients estimated under the constraint conditions will be quite different from the coefficients estimated without constraints.

Furthermore, the constrained model should fit the observed data significantly worse than the unconstrained model.

To test whether constraining parameters across genders would significantly worsen model fit, I fit an actor model estimating the associations between husbands' and wives' own predictor variables and their own probabilities of having an advance directive (Model 1). This first model allowed all parameters to be freely estimated. I then re-estimated the actor model constraining paths to be equal for husbands and wives (Model 2). As reported in the next chapter, these constraints did not significantly worsen the model fit, so the constrained actor model (Model 2) was used for subsequent comparisons.

I then tested the proposition that advance directive completion is associated with personal and spousal factors by fitting an actor-partner model. This model estimated the relationships between participants' predictor variables and both their own and their spouses' probabilities of possessing advance directives (Model 3). Actor effects were constrained to be equal across genders and partner effects were freely estimated. This model was compared to the constrained actor model (Model 2).

I tested the proposition that partner effects would differ by gender by estimating an actor-partner model with actor and partner effects constrained to be equal across husbands and wives (Model 4). This model was compared to Model 3 in which partner effects were freely estimated.

Model fit was assessed based on three fit indices:  $\chi^2$ , root mean square error of approximation (RMSEA), and comparative fit index (CFI). A highly-cited dissertation seems to be the most authoritative source on interpreting fit indices when outcome variables are categorical. Based on studies using both simulated and real data, Yu (2002) found that when sample size is at least 250, CFI values equal to or greater than .96 and RMSEA values less than

or equal to .05 indicate good model fit. Yu also recommended using CFI rather than the Tucker Lewis Index (TLI). Ideally, the  $\chi^2$  should also be non-significant, indicating that the model is not significantly worse than a saturated model in which all paths are estimated with no degrees of freedom remaining. However, this test is the most conservative of the three and is often statistically significant even for well-fitting models, particularly when sample size is large (Brown, 2015).

***Dyadic Patterns.*** Following global testing of the APIM, I estimated a saturated model in which all actor and partner effects were freely estimated. Confidence intervals were generated using bootstrapping (5000 draws). At this stage of the analysis, the focus was on the specific coefficients within the model, both their statistical significance and whether they differed significantly by gender.

I used the saturated model to classify associations between predictor variables and advance directive completion into one of four dyadic patterns: actor effect, couple effect, social comparison (or contrast effect), and partner effect (Kenny & Ledermann, 2010). The actor effect dyadic pattern is defined as a significant (non-zero) actor effect and non-significant partner effect. The couple effect pattern is demonstrated when both actor and partner effects are significant and in the same direction. The social comparison pattern is similar to the couple effect in that both actor and partner effects are significant, but in opposite directions. The partner effect pattern is indicated when the partner effect is significant and the actor effect is non-significant.

I also tested for gender differences in actor and partner effects by constraining each effect to be equal and examining changes in  $\chi^2$  using the DIFFTEST function. A statistically insignificant  $\chi^2$  difference indicated that the effect was equivalent for men and women, whereas a significant  $\chi^2$  difference suggested a gender difference (Fitzpatrick, Gareau, Lafontaine, &

Gaudreau, 2016). Unlike the global tests in which all actor and/or all partner effects were constrained to be equal for men and women simultaneously, this process allowed me to examine gender differences for each effect separately.

## Chapter 5

### Quantitative Study: Results

#### Examination of the Data

**Non-independence.** Non-independence of husbands' and wives' values on predictor, outcome, and auxiliary variables was evaluated using Pearson correlation and Cohen's kappa tests. Both measures use a -1 to 1 scale with 0 indicating no relationship. Measures of dyadic non-independence for all variables are reported in Table 4.

The ages of husbands and wives were highly correlated,  $r = .80$ . Race and ethnicity were also strongly associated, with 96% agreement between spouses,  $\kappa = .88$ . There was substantially more agreement than would be expected by chance between husbands' and wives' advance directive status,  $\kappa = .56$ , education,  $\kappa = .29$ , and whether or not husbands and wives had regular health care providers,  $\kappa = .20$ . Self-reported health status and hospitalization/outpatient surgery displayed a greater degree of independence, with kappa values nearer to zero and observed agreement closer to what would be expected by chance.

Table 4  
*Dyadic Non-independence*

Variable	Observed Agreement %	Expected Agreement %	$\kappa$ (SE)	$r$
Advance directive	78.4	50.8	.56 (.02)	-
Age	-	-	-	.80
Education	47.9	27.0	.29 (.01)	-
Race/ethnicity	96.3	68.3	.88 (.02)	-
Self-reported health status	31.9	26.4	.07 (.01)	-
Regular health care provider	84.3	80.4	.20 (.02)	-
Hospitalization/outpatient surgery	77.5	76.3	.05 (.02)	-

*Note.* Independence was measured with the Pearson product-moment correlation coefficient for continuous variables and Cohen's kappa for categorical and ordinal variables.

These results indicated that the data violated the assumption of independence for at least some variables. This lack of independence must be accounted for to generate unbiased point

estimates and confidence intervals. Furthermore, the extremely high level of agreement between husbands' and wives' race/ethnicity made it impossible to distinguish between actor effects and partner effects and raised concerns about multicollinearity.

**Missing data.** Five percent of dyads were missing values on one or more variables. The highest rate of missing data was for the hospitalization and/or outpatient surgery variables, with 2% of men and 2% of women lacking information. All other variables had rates of missingness of less than 1%. Missing values were distributed throughout the data matrix, indicating a general missing data pattern (Enders, 2010). Rates of missingness under 5% should not bias results even when listwise deletion is used. However, to check for possible bias, I reran all models using multiple imputation and compared the results with those from a single dataset. The differences observed are reported at the end of this chapter.

**Power.** Crosstabs for all possible combinations of categorical variables were examined. There were no empty cells and no expected values less than five, indicating sufficient power (Agresti, 1996).

**Sample characteristics.** The full sample was made up of 2,243 heterosexual married couples in which both spouses were at least 65 years old, had been married to their current spouses for at least 10 years, and were living together in a non-nursing home setting at the time of the 2012 HRS interviews. All sample characteristics are presented in Table 5.

Table 5  
Sample Characteristics

Variable	Men (n = 2,243)	Women (n = 2,243)	<i>p</i>
Mean marriage duration in years (SD)	48.0 (12.3)		-
Has advance directive %	57	56	.71
Mean age (SD)	76.4 (6.1)	73.7 (5.9)	< .001
Education %			
Less than high school	19	16	< .001
High school/GED	35	41	
Some college	18	24	
College degree or higher	28	19	
Race/ethnicity %			
Non-Hispanic White	82	82	.93
Non-Hispanic African American	8	8	
Hispanic	8	8	
Other	2	2	
Self-reported health status %			
Excellent	7	8	< .001
Very good	30	34	
Good	34	34	
Fair	19	18	
Poor	9	6	
Has a regular health care provider %	88	90	.08
Hospitalization/outpatient surgery %	87	85	.06

*Note.* *P*-values were calculated using paired sample t-test for continuous variables, the generalized McNemar's test for non-ordered categorical variables, and the Wilcoxon signed-rank test for ordinal variables. Percentages may not add to 100% due to rounding error.

The mean marriage duration was 48 years. Women were on average approximately three years younger, with a mean age of 73.7 compared to 76.4 for men. Eighty-two percent of men and women were non-Hispanic White, 8% were non-Hispanic African American, 8% were Hispanic, and 2% were classified as Other. Men and women differed in terms of education, with more men having less than a high school education (19% of men vs. 16% of women), but also more men having a college degree or higher (28% of men vs. 19% of women). In contrast, more women had either a high school degree/GED (41% of women vs. 35% of men) or some college (24% of women vs. 18% of men).

The women in the sample were on average healthier, with 76% of women reporting having good, very good or excellent health compared to 72% of men. In terms of health care utilization, slightly more women had a regular health care provider (88% of men vs. 90% of women) and a slightly higher percentage of men had been hospitalized or had undergone outpatient surgery (87% of men vs. 85% of women). Neither of these differences were statistically significant at the 95% confidence level. However, among those who reported having a regular place where they received health care, significantly more women (85%) than men (80%) stated that their regular health care provider was a doctor's office or HMO as opposed to a clinic, health center, hospital outpatient department, or some other place.

The rates of advance directive completion were approximately equal across genders, with 57% of men and 56% of women reporting having a living will, durable power of attorney for health care, or both. The crosstab in Table 6 illustrates how many couples shared the same advance directive status. Of the 2,206 couples for whom data were available, both spouses had advance directives in 46% of couples and both did not have advance directives in 33% of couples. In the 22% of couples with non-matching ACP status, 49% had wives with advance directives and 51% had husbands with advance directives.

Table 6  
*Crosstab of Advance Directive Completion by Husbands and Wives (n = 2,206 couples)*

Advance directive (husbands)	Advance directive (wives)		Total
	No	Yes	
No	725 (33%)	234 (11%)	959 (43%)
Yes	242 (11%)	1,005 (46%)	1,247 (57%)
Total	967 (44%)	1,239 (56%)	2,206 (100%)

In summary, the women in the sample were on average younger and healthier than the men. They also tended to have moderate levels of education while men were more likely to have either low or high levels of education. Rates of health care utilization and advance directive



completion were fairly equal across genders. Approximately 80% of spouses had the same advance directive status. In couples that differed on advance directive status, men and women were equally likely to have an advance directive when their spouses did not.

**Bivariate analyses.** Tests of the bivariate relationships between the advance directive status of husbands and wives and each predictor variable were conducted using simple logistic regression. Odds ratios, confidence intervals, and *p*-values are presented in Table 7.

**Actor effects.** For men, the significant actor effects associated with higher odds of having an advance directive were age, *OR* = 1.06, education, *OR* = 1.60, hospitalization and/or outpatient surgery, *OR* = 1.77, and having a regular health care provider, *OR* = 1.67. These results are consistent with findings from previous studies. There were no significant actor effects that negatively impacted men's odds of advance directive completion.

For women, the positive significant actor effects were age, *OR* = 1.07, education, *OR* = 1.50, hospitalization and/or outpatient surgery, *OR* = 1.36, and having a regular health care provider, *OR* = 1.68. These findings are consistent with prior research. In addition, poorer health as measured by self-reported health status decreased the odds of having an advance directive, *OR* = .87. This negative relationship was somewhat surprising and not consistent with several studies that have found worse health to be associated with a higher likelihood of having an advance directive (Bischoff et al., 2013; Carr, 2012b; Morrison et al., 1998; Murphy et al., 1996; Rao et al., 2014; Sudore et al., 2008).

**Partner effects.** Turning to partner effects, the likelihood of having an advance directive for men was positively associated with wives' age, *OR* = 1.06, wives' education, *OR* = 1.43, and wives' regular health care provider, *OR* = 1.68. Wives' poorer self-reported health status lowered husbands' odds of possessing advance directives, *OR* = .77.

Positive partner effects for women were husbands' age,  $OR = 1.06$ , husband's education,  $OR = 1.54$ , husband's hospitalization and/or outpatient surgery,  $OR = 1.71$ , and husband's regular health care provider,  $OR = 1.38$ . Husbands' poorer self-reported health status lowered wives' odds,  $OR = .86$ .

Table 7

*Bivariate Relationships between Independent Variables and Odds of Having an Advance Directive for Husbands and Wives*

Variable	Advance directive (husbands)		Advance directive (wives)	
	<i>OR</i>	[95% CI]	<i>OR</i>	[95% CI]
Age				
Husband	1.06***	[1.04, 1.07]	1.06***	[1.05, 1.08]
Wife	1.06***	[1.05, 1.08]	1.07***	[1.05, 1.08]
Education				
Husband	1.60***	[1.48, 1.74]	1.54***	[1.42, 1.67]
Wife	1.43***	[1.31, 1.56]	1.50***	[1.37, 1.64]
Poorer SRH				
Husband	.94	[.87, 1.01]	.86***	[.79, .93]
Wife	.77***	[.71, .84]	.87***	[.80, .94]
Hospital / surgery				
Husband	1.77***	[1.37, 2.28]	1.71***	[1.32, 2.20]
Wife	1.07	[.84, 1.36]	1.36*	[1.07, 1.72]
Regular HCP				
Husband	1.67***	[1.29, 2.17]	1.39*	[1.07, 1.80]
Wife	1.68***	[1.27, 2.22]	1.68***	[1.28-2.22]

*Note.* *OR* = odds ratio; SE = standard error; CI = confidence interval; SRH = self-reported health status; HCP = health care provider. Estimates calculated using logistic regression.

†  $p < .10$ . \*  $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$ .

## Path Analyses

Table 8 summarizes the  $\chi^2$ ,  $\chi^2$  difference tests, RMSEA, and CFI values for the global model comparisons. The coefficients for all four models are presented in Table 9.

**Actor models.** An actor model (Model 1) was estimated by simultaneously regressing husbands' advance directive status on husbands' predictor variables and wives' advance directive status on wives' predictor variables, freely estimating all coefficients,  $\chi^2(10, 2135) = 93.32$ ,  $p < .001$ , RMSEA = .062, CFI = .926. The predictor variables were free to covary and the

Table 8  
Global Model Comparisons ( $n = 2,135$  couples)

Parent	Nested	$\chi^2$ diff	RMSEA [90% CI]		CFI	
			Parent	Nested	Parent	Nested
Model 1 <sup>a</sup>	Model 2 <sup>b</sup>	8.73	.062 [.051, .074]	.047 [.037, .057]	.926	.938
Model 3 <sup>c</sup>	Model 2 <sup>b</sup>	93.32***	.019 [0, .039]	.047 [.037, .057]	.997	.938
Model 3 <sup>c</sup>	Model 4 <sup>d</sup>	12.83*	.019 [0, .039]	.021 [.006, .035]	.997	.992

<sup>a</sup> Actor effects freely estimated, partner effects fixed to 0.

<sup>b</sup> Actor effects constrained to be equal across genders, partner effects fixed to 0.

<sup>c</sup> Actor effects constrained to be equal across genders, partner effects freely estimated.

<sup>d</sup> Actor effects constrained to be equal across genders, partner effects constrained to be equal across genders.

\*  $p < .05$ . \*\*\*  $p < .001$ .

marginal covariance between husbands' and wives' probabilities of advance directive possession was estimated by loading a factor on the two outcome variables. All partner effects were fixed to zero. For categorical analysis, the thresholds for good model fit are RMSEA  $\leq .05$  and CFI  $\geq .96$  (Yu, 2002).

A second actor model (Model 2) was estimated with husbands' and wives' coefficients constrained to be equal on like predictor variables,  $\chi^2(15, 2135) = 85.02, p < .001$ , RMSEA = .047, CFI = .938. The model fit was slightly better as measured by RMSEA and CFI, and the adjusted  $\chi^2$  difference between the unconstrained actor model and the constrained actor model was not significant ( $p = .12$ ). These results indicated that constraining the parameters to be equal across genders did not worsen the model. Because Model 2 had greater power, actor effects were constrained to be equal across genders in subsequent model comparisons.

**Actor-partner models.** I then fit an actor-partner model (Model 3) constraining actor effects to be equal across husbands and wives and allowing partner effects to be freely estimated,  $\chi^2(5, 2135) = 8.73, p = .12$ , RMSEA = .019, CFI = .997. This model fit the data extremely well, with a non-significant  $\chi^2$  and fit indices well within the recommended ranges. Furthermore, Model 2 was significantly worse-fitting than Model 3 ( $p < .001$ ), supporting the proposition that both personal and spousal factors are associated with advance directive completion.

To test globally whether partner effects were significantly different for men and women, I fit a fourth model (Model 4) constraining partner effects to be equal across husbands and wives as well as actor effects,  $\chi^2(10, 2135) = 19.34, p = .04$ , RMSEA = .021, CFI = .992. This model also fit the data quite well, although there was some reduction in model fit with the  $\chi^2$  difference significant at  $p = .03$  and some worsening of all three fit indices. These results suggest that there are some gender differences in partner effects.

Table 9  
*Unstandardized Probit Coefficients for Actor and Actor-Partner Models (n = 2,135 couples)*

Variable	Model 1 <sup>a</sup>	Model 2 <sup>b</sup>	Model 3 <sup>c</sup>	Model 4 <sup>d</sup>
Age				
H→AD(H)	.03*	.04***	.04***	.04***
W→AD(W)	.05**	.04***	.04***	.04***
H→AD(W)	-	-	.04**	.05***
W→AD(H)	-	-	.06***	.05***
Education				
H→AD(H)	.44***	.34***	.34***	.34***
W→AD(W)	.23**	.34***	.34***	.34***
H→AD(W)	-	-	.36***	.26***
W→AD(H)	-	-	.14*	.26***
Poorer SRH				
H→AD(H)	.03	-.03	-.03	-.03
W→AD(W)	-.10 <sup>†</sup>	-.03	-.03	-.03
H→AD(W)	-	-	-.13*	-.18***
W→AD(H)	-	-	-.24***	-.18***
Hospital/surgery				
H→AD(H)	.49**	.36**	.36**	.36**
W→AD(W)	.24	.36**	.36**	.36**
H→AD(W)	-	-	.54**	.30*
W→AD(H)	-	-	.01	.30*
Regular HCP				
H→AD(H)	.22	.32**	.32**	.32**
W→AD(W)	.43*	.32**	.32**	.32**
H→AD(W)	-	-	.02	.19
W→AD(H)	-	-	.36*	.19

Note. H = husband; W = wife; AD = advance directive; SRH = self-reported health status; HCP = health care provider. Shaded rows are partner effects.

<sup>a</sup> Actor effects freely estimated, partner effects fixed to 0.

<sup>b</sup> Actor effects constrained to be equal across genders, partner effects fixed to 0.

<sup>c</sup> Actor effects constrained to be equal across genders, partner effects freely estimated.

<sup>d</sup> Actor effects constrained to be equal across genders, partner effects constrained to be equal across genders.

<sup>†</sup>  $p < .10$ . \*  $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$ .

**Dyadic patterns and gender differences.** The global model comparisons established that the APIM was a better fitting model than the model that only estimated actor effects. It also indicated that, in the aggregate, actor effects were equivalent but partner effects differed. To examine the specific actor and partner effects as well as gender differences, I estimated a saturated APIM that freely estimated all actor and partner effects. Each independent variable was classified into one of four dyadic patterns: actor-oriented, partner-oriented, couple-oriented, or social comparison (or contrast) (Kenny et al., 2006). The actor-oriented pattern is defined as a significant (non-zero) actor effect and non-significant partner effect. The partner-oriented pattern is present when the partner effect is significant and the actor effect is non-significant. A couple-oriented pattern is demonstrated when both actor and partner effects are significant and in the same direction. The social comparison or contrast effect is present when both actor and partner effects are significant but in opposite directions.

To test for gender differences, I constrained each actor and each partner effect to be equal for men and women and observed whether the constraint significantly worsened model fit compared to the saturated model as indicated by a significant  $\chi^2$  (Fitzpatrick et al., 2016; Kenny et al., 2006). Unstandardized probit coefficients,  $\chi^2$  statistics for gender differences, and dyadic patterns for the saturated APIM are presented in Table 10. A path diagram of the APIM with all actor and partner effects freely estimated is presented in Figure 3.

Table 10

*Unstandardized Probit Coefficients, Gender Differences, and Dyadic Patterns for the Saturated Actor-Partner Model (n = 2,135 couples)*

Variable	APIM		Gender difference		Dyadic pattern	
	AD(H)	AD(W)	Actor	Partner	AD(H)	AD(W)
	<i>b</i> [95% CI]	<i>b</i> [95% CI]	$\chi^2$ difference	$\chi^2$ difference		
Age						
Husband	.03* [.01, .06]	.04** [.02, .07]	.42	.20	Couple	Couple
Wife	.06** [.03, .08]	.05** [.02, .08]	H $\approx$ W	H $\approx$ W		
Education						
Husband	.44*** [.33, .55]	.36*** [.25, .47]	4.30*	4.64*	Couple	Couple
Wife	.14* [.02, .25]	.23** [.11, .35]	H > W	H > W		
Poorer SRH						
Husband	.03 [-.06, .12]	-.13* [-.22, -.04]	2.37	2.00	Partner	Partner
Wife	-.24*** [-.34, -.14]	-.10 <sup>†</sup> [-.20, -.01]	H $\approx$ W	H $\approx$ W		
Hospital/surgery						
Husband	.49** [.20, .78]	.54** [.26, .82]	1.16	5.01*	Actor	Partner
Wife	.01 [-.26, .27]	.24 [-.03, .49]	H $\approx$ W	H > W		
Regular HCP						
Husband	.22 [-.08, .52]	.02 [-.26, .31]	.67	1.64	None	Actor
Wife	.36 <sup>†</sup> [.05, .68]	.43* [.10, .74]	H $\approx$ W	H $\approx$ W		

Note. CI = confidence interval; AD = advance directive; H = husband; W = wife; SRH = self-reported health status; HCP = health care provider. Shaded areas indicate partner effects. Gender differences tested by constraining each effect to be equal across genders and comparing model fit to saturated model using  $\chi^2$  difference test.

<sup>†</sup>  $p < .10$ . \*  $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$ .

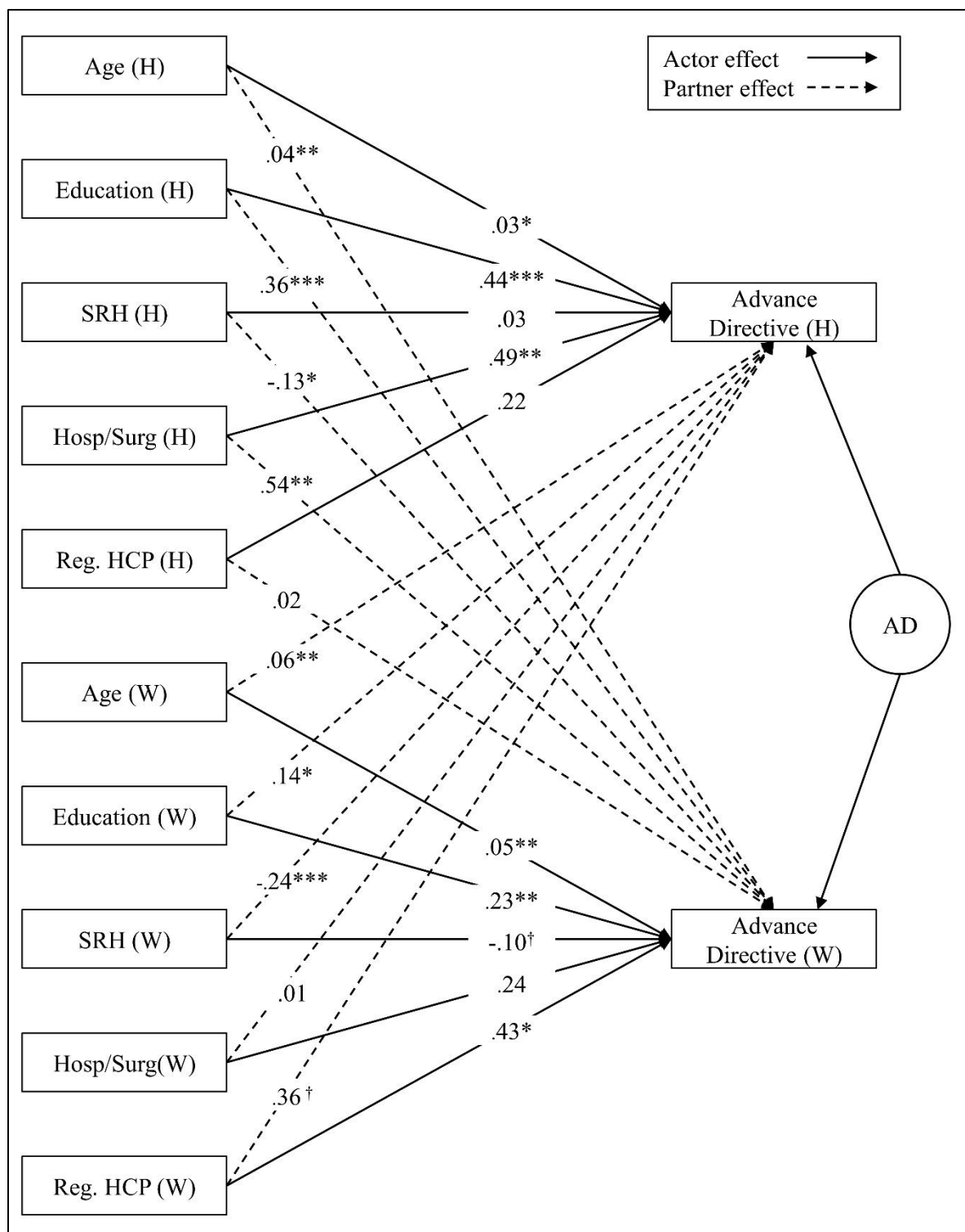


Figure 3. Saturated actor-partner model with unstandardized probit coefficients. H = husband; W = wife; SRH = self-reported health status; Hosp/Surg = hospitalization and/or outpatient surgery; HCP = health care provider. †  $p < .10$ . \*  $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$ .

**Age.** Both actor and partner effects were significant for age, indicating a couple-oriented pattern for men and women. An individual's own age was positively associated with having an advance directive. A spouse's age was also positively associated with having an advance directive. There were no statistically significant gender differences in actor or partner effects.

**Education.** Both actor and partner effects were significant for education, indicating a couple-oriented pattern for men and women. An individual's own education was positively associated with having an advance directive. In addition, one's spouse's education was positively associated with having an advance directive. The actor and partner effects were stronger for men's education than women's education.

**Self-reported health status.** Self-reported health was negatively associated with spouses' advance directive completion but not one's own (except for a marginally significant actor effect for women), indicating a partner-oriented pattern. The worse a spouse's health, the lower the probability of having an advance directive. There were no statistically significant gender differences in actor or partner effects.

**Hospitalization and/or outpatient surgery.** When men had been hospitalized or had undergone outpatient surgery, the probability of having an advance directive increased for both the men and their wives. However, women's hospitalization or outpatient surgery did not significantly change either their own or their spouses' probabilities of completing advance directives. Although the actor effect was statistically significant for men but not women, the two coefficients were not significantly different from each other. The partner effect of men's hospitalization or outpatient surgery was stronger than women's hospitalization or outpatient surgery.



**Regular health care provider.** When a woman had a regular health care provider, her probability of having an advance directive increased. There was also a marginally significant positive effect on her husband's likelihood of having an advance directive. Whether or not a man had a regular health care provider did not significantly change either his own or his spouse's probabilities of completing advance directives. However, when these actor and partner effects were compared across genders, there were no statistically significant differences observed.

**Effect of missing data.** Approximately 5% of the couples were excluded from the multivariate analyses due to missing data on one or more variables. This reduced the sample size from 2,243 to 2,135 couples. To determine what effect missing data may have had, I re-estimated all four nested models as well as the saturated APIM using multiple imputation (100 datasets) to handle missing data. The fit indices were almost identical. There were only minor differences in coefficients and  $p$ -values.

In Model 1, women's hospitalization was marginally associated with their own advance directive completion at  $p < .10$  when data were imputed, but was not significant in the non-imputed data. Women's self-reported health status was not significantly predictive of their written ACP in the imputed data but was marginally significant at  $p < .10$  in the non-imputed data. In Model 3, women's education was significantly related to their husbands' advance directive completion at  $p < .05$  in non-imputed data but only marginally significant at  $p < .10$  in imputed data. Men's self-reported health was significantly predictive of their wives' advance directive completion at  $p < .05$  for non-imputed data but only marginally significant at  $p < .10$  for imputed data.

Comparing the non-imputed and imputed saturated models, the coefficients were almost identical, but there were a few changes in statistical significance. Women's education was

related to their spouses' advance directive completion at  $p < .05$  in non-imputed data but only marginally significant at  $p < .10$  for imputed data. The actor effect of women's health status was marginally significant at  $p < .10$  in non-imputed data and became non-significant in imputed data. The relationship between women's health status and their husbands' advance directive completion was significant at  $p < .05$  in non-imputed data but only marginally significant at  $p < .10$  in imputed data. The actor effect of women's hospitalization was not significant in non-imputed data and became only marginally significant at  $p < .10$  in imputed data.

It does not appear that missing data biased the overall results and seems to have made a slight difference only when findings were on the cusp of statistical significance. However, the saturated model using imputed data would have led to two different conclusions regarding dyadic patterns. First, because the partner effect of women's education was only marginally significant in imputed data, women's education would have been classified as exhibiting an actor-oriented pattern as opposed to a couple effect. Second, the partner effect of men's self-reported health status was only marginally significant in imputed data, so men's health would have been classified as having no effect on either spouse rather than a partner-oriented pattern.

### **Implications for the Proposed Relational Model**

Examining the results through the proposed relational model, one can see that the predisposing individual-level characteristics of age and education exhibited both actor and partner effects. The individual-level need factor of self-reported health status displayed only negative partner effects. These findings support the inclusion of the two individual-level inner circles in the model (labeled P1 and P2 for person 1 and person 2) and suggest that spouses exert both positive and negative influence on one another's ACP.

Furthermore, at least one of the two organizational-level factors displayed actor and partner effects, albeit with important gender differences. Men's interactions with health care providers in the context of hospitalization or outpatient surgery was positively associated with their own and their wives' advance directive completion. In contrast, women's hospitalization or outpatient surgery was not associated with ACP for either spouse, and having a regular health care provider was positively associated only with a woman's own advance directive completion. These results, although mixed, support the inclusion of the overlapping organizational-level context layers in the relational model.

What the quantitative data cannot adequately address is the central element of the proposed model consisting of stages connected by intertwined arrows. This aspect of the relational model represents the process through which older married adults influence and are influenced by their spouses as they decide whether and when to complete advance directives. The qualitative interviews with older married couples described in the next two chapters provide additional data to evaluate the usefulness and applicability of this element of the proposed model. They also begin to shed light on some of the potential reasons for gender differences observed in the quantitative data.

## **Chapter 6**

### **Qualitative Study: Methods**

The quantitative study showed that advance directive completion by older married adults was associated with personal and spousal factors at the individual and organizational context levels (contextual interdependence). However, there were no data regarding the timing of advance directive completion or the process leading up to ACP. To complement the quantitative study (Brannen, 2004), I conducted eight semi-structured interviews with four older married couples who had engaged in end-of-life planning. My goals were to better understand the events and circumstances that enabled, motivated, or delayed advance directive completion and to assess to what extent these were personal, partner, or joint factors.

#### **Phenomenological Methodology**

I used a phenomenological approach to collect and analyze this qualitative data. Qualitative phenomenology, rooted in modern European philosophy, seeks to understand common meanings and features of an event or “phenomena” by collecting and comparing personal descriptions from individuals who have firsthand knowledge of the phenomena under study (Starks & Trinidad, 2007). Phenomenological research “focuses on everyday subjective meaning and experience” with the aim of discovering “how objects and experiences are meaningfully constituted and communicated in the world of everyday life” (Holstein & Gubrium, 1994, p. 264).

Phenomenological studies involve relatively small numbers of people – a range of five to 25 participants is the recommended sample size – who provide detailed descriptions of their personal experiences (Creswell, 2007). The primary role of the interviewer is to encourage the interviewee to elaborate and clarify through follow-up questions as the participant describes a

lived experience (Starks & Trinidad, 2007). Phenomenological qualitative analysis involves summarizing what participants said in order to identify consistent characteristics or elements of the studied phenomena across the different accounts. One can think of the analytical process as a gradual distillation of raw narratives down to their essences. The researcher tries to “bracket” his or her own “life world,” setting aside one’s own taken-for-granted orientation in order to focus on how participants interpretively produce their own realities (Holstein & Gubrium, 1994).

### **Participant Recruitment**

I limited participation to couples who had been married ten years or longer, were at least 65 years old (although one spouse was 64), and were living together in a non-institutional setting. These requirements were designed to make the qualitative study sample comparable to the HRS sample in the quantitative study. Initially, I tried to limit the sample to couples in which one or both spouses had completed an advance directive during the prior 12 months. However, recruitment difficulties led me to relax this time restriction.

Participants were recruited between February and June of 2016. Flyers were posted at senior centers, independent senior housing communities, and public places such as grocery stores and libraries. On two separate occasions, I spoke about the research project to gatherings of residents of a large retirement community. Display advertisements were placed in *60 & Better* (a free newsletter published by Douglas County Senior Services), *The Call* (an African American newspaper in Kansas City), and *Amazing Aging!* (a free newsletter distributed by the Jayhawk Area Agency on Aging).

Recruitment was not limited to married couples. Twenty-one people contacted me about participating in the study. I interviewed a total of 15 participants, eight of whom were part of spousal pairs. Of the six people who responded to the notice but did not enroll, four decided not

to participate after learning more about the study, one was seeking assistance with completing an advance directive, and one did not remember the circumstances leading up to completing an advance directive because it had been too long ago. The present study uses data from the interviews with the eight married participants. The interviews with non-married participants were helpful in testing and adapting the interview protocol and identifying researcher assumptions.

### **Ethical Considerations**

The study was approved by the University of Kansas Institutional Review Board (IRB Study #00003717, approved February 11, 2016). Before each interview, I went over a written consent form with the participant, obtained the participant's signature, and provided the participant with an unsigned copy of the consent form. Interviewees were given \$20 immediately before the interviews began and informed that they could keep the money regardless of whether they refused to respond to a question or terminated the interview. I also made available a printed handout with state-specific information about advance directives produced by the National Hospice and Palliative Care Organization (downloaded from [www.caringinfo.org](http://www.caringinfo.org)). I offered this handout after the interview was completed.

Dyadic qualitative studies present several unique ethical concerns. Confidentiality may be inadvertently breached if the interviewer reveals knowledge gained during a prior interview with one partner through the questions asked of the other (Mellor, Slaymaker, & Cleland, 2013). It is also likely that partners will be able to recognize one another in published descriptions or quotations, even when names and other identifying information are changed (Eisikovits & Koren, 2010). Participants may actively seek out information about their partners from the researcher, putting the interviewer in a difficult "stuck in the middle" situation (Forbat & Henderson, 2003).

I informed participants ahead of time that I would not disclose confidential information to or about their spouses and that I would change their names and non-relevant factual information in any report in which they would be quoted or described. I also cautioned it might be possible for their spouses to nevertheless identify them. During the interviews, I made a concerted effort not to reveal information that I had gained during one partner interview through my questions or comments directed at the other partner. This sometimes required that I ask questions to which I already knew the answers.

### **The Choice of Joint or Separate Interviews**

Studies involving husbands and wives raise the special research design issue of whether to conduct separate or joint interviews. One advantage of interviewing dyad members separately is that each individual can speak unimpeded by the other's presence. This may be particularly important when discussing sensitive or private topics (Valentine, 1999). Separate interviews also permit both individual-level and dyadic-level analyses as well as triangulation through comparison of two accounts of a common experience.

An advantage of interviewing a couple together is that the researcher obtains not just two separate accounts of the same subject matter, but rather a blended narrative that is co-constructed by the couple. Interaction may stimulate new thoughts and ideas as the participants listen and respond to one another, so that what emerges is likely different from what the two participants would have said separately (Allan, 1980). When couple dynamics or communication patterns are of interest, observing how two people negotiate the production of a shared narrative can provide valuable information (Valentine, 1999). Joint interviews can also permit individuals with disabilities to participate in research with the assistance of a partner (Caldwell, 2014).

There are downsides to joint interviews as well. The presence of another can inhibit disclosure either because of the tendency for one to dominate or reluctance to speak openly in front of the other person (Barnett, Guell, & Ogilvie, 2013). Joint interviews raise ethical concerns including lack of within-dyad confidentiality (Morgan, Ataie, Carder, & Hoffman, 2013), inadvertent exposure of relationship tensions or conflict (Valentine, 1999), and questions of continued informed consent if disagreements arise during the interview about what information may or may not be disclosed to the researcher (Larossa, Bennett, & Gelles, 1981).

After considering all of these advantages and disadvantages, I opted to conduct separate interviews for the following reasons. My primary interest was in each participant's personal experiences of engaging in ACP. Separate interviews would allow for comparisons to be made across all project participants as well as intra-couple and inter-couple analyses. I also feared that the relational aspects of couples' ACP would be exaggerated if spouses engaged in joint storytelling, thereby biasing the results. Finally, I anticipated that participants would feel more comfortable discussing any disagreements or frustrations they had with their spouses if interviewed alone.

I planned to interview all participants privately. However, one husband and wife dyad (Nancy and Ned) opted to be present during one another's interviews. This was in part because of Nancy's physical and cognitive limitations that made her hesitant to be interviewed alone. In fact, she initially declined to participate at all, but then consented after watching her husband's interview. All of the other interviews were conducted without the other spouse present, although occasionally our conversations were interrupted when a partner briefly entered the room.



## **Interview Structure**

I developed a semi-structured interview protocol to guide the conversations with participants about their advance directive completion and the events leading up to it (see Appendix A). Each interview began with some general questions about employment and family. I then asked participants to describe how they learned about advance directives, how they came to complete them, and the details of the process and circumstances of completing the forms. Following these open-ended questions, I used a card sorting exercise to prompt further reflection and elaboration. Visual techniques can complement a more traditional interview by serving as an aide-memoire, encouraging storytelling, and eliciting additional insights from participants (Sheridan, Chamberlain, & Dupuis, 2011). This card sorting exercise is described in more detail below. I ended each interview with a general open-ended question about when is the right time to complete an advance directive and a few background questions about age, education, religion, race/ethnicity, and health status.

**Card sorting procedures.** The interviewee was first given a stack of 29 cards, each briefly describing a life event or circumstance that the participant could have personally experienced. For example, one card read, “I was diagnosed with an illness or condition.” The participant was subsequently given a second stack of 29 cards. These described similar events or circumstances that may have happened in his or her spouse’s life such as, “My spouse was diagnosed with an illness or condition.” A list of the statements on both sets of cards can be found in Appendix B.

Originally, I envisioned the card sorting exercise as a timeline construction in which participants would first identify the events that had occurred in their lives and the lives of their spouses around the time they completed their advance directives, place those events in

chronological order, and then identify which events had played a role in their decisions to engage in ACP when they did. However, my assumption that narratives would follow a linear timeline was quickly dispelled. Furthermore, when more than a few years had passed since a participant completed an advance directive, I found that an unwieldy number of cards were placed on the table. Therefore, I adapted the exercise as follows.

Participants who had completed an advance directive in the past year were asked to place on the table the cards describing any events or circumstances that had happened in their own lives during the previous two years. I then gave them the second stack of cards and asked them to place on the table any events that had occurred in their spouse's life during the past two years. When all the cards were laid out, I asked them to group cards that corresponded to the same event or circumstance. I then gave them a stack of pennies and asked them to place a penny on each event or circumstance that in some way influenced their decision to engage in ACP when they did.

For those whose ACP occurred more than a year earlier, I asked them to place on the table any event cards that in some way influenced their decisions to engage in ACP when they did. I then repeated this request regarding the spousal event cards. Once the cards were laid on the table, I asked the participants to group any cards that referred to the same event or circumstance.

Further adjustments were necessary in the one interview with a participant who had not completed an advance directive. I asked her to place on the table any events that happened to her in the past two years. I then asked if any of these had led her to consider engaging in ACP. We then repeated this discussion using the spousal event cards.

After discussing the cards on the table, all participants were asked if there were other events or circumstances that played a role in their decision to engage in ACP. I also probed for any obstacles that may have prevented them from completing advance directives earlier or, in the case of the participant who did not have an advance directive, at all.

## **Documentation**

Interviews were recorded and transcribed verbatim. I also took photos of the card exercises and made observatory notes immediately following each interview. Although a few participants brought their advance directive forms with them to the interview, I did not request to see copies because I did not want to ask participants to reveal confidential health information not central to my research question. Since I was more interested in the process and events leading up to ACP than in the decisions made, it was not necessary to review participants' advance directives. I also did not want to be put in the position of advising participants about potential problems with their documents, something I would have felt ethically obligated to do if I had reviewed the forms and observed errors in drafting or execution. By choosing not to look at participants' advance directives, however, I could not verify whether they had actually executed the planning documents they reported completing.

## **Analysis**

In analyzing the interview transcripts, I was guided by the phenomenological process outlined by Moustakas (1994) that gradually moves from description to interpretation and from individual-level analysis to composite-level analysis.

**Individual textual and structural descriptions.** First, I carefully read each transcript and assigned a brief descriptor to each passage. In grounded theory, this is referred to as open coding (Charmaz, 2006). Phenomenology uses the term *horizontalization* to describe the process

of labeling each reference to the phenomenon being studied in order to begin to identify emergent themes or attributes (Moustakas, 1994). Second, I clustered similarly-labeled passages within each transcript to construct a textual description of each participant's narrative. I then summarized in my own words and with participants' quotations the ACP experience of each interviewee. Finally, I organized these individual descriptions using consistent categorical headings based on common themes that emerged from multiple interviews.

I also drafted a structural description of each participant's narrative by carefully rereading each transcript and my own post-interview observations. While a textual description is limited to the participant's account of events, in the structural description the researcher can insert her own interpretations and identify elements that may not have been explicitly expressed by the interviewee. Once I had written my interpretations of each narrative, I identified crosscutting themes and organized the structural descriptions using a consistent heading system based on these themes. At the end of this phase of analysis, I had eight individual textual descriptions and eight individual structural descriptions.

**Dyadic descriptions.** With separate dyadic interviews, one challenge is to move beyond merely presenting two individuals' versions of the same event. To adapt phenomenological methods of analysis to dyadic data, I drew on procedures used by Eisikovits and Koren (2010) in their phenomenological study of older adults in new marital relationships. Following individual analysis of each transcript, the researchers compared partners' narratives by identifying similarities and differences between the two versions. This led to the reconstruction of themes that had emerged from the individual transcripts as well as the addition of new dyadic themes. The researchers paid particular attention to the degree of "I-ness" and "we-ness" in the narratives. "This can be viewed when presenting the individual perspective of each member of

the dyad alongside the dyadic perspective created by the researcher as a third party. Such a procedure enables the reader to distinguish between what belongs to I-ness from an individual perspective and what is unique to the dyadic perspective of we-ness.” (Eisikovits & Koren, 2010, p. 4). The result is three separate but overlapping versions of a phenomenon for each couple, two at the individual level as rendered by each partner and a third dyadic one constructed by the researcher.

By organizing the individual textual and structural descriptions using common heading systems, I was able to more easily compare descriptions between spouses to identify similarities, differences, and areas of overlap. I wrote in my own words a dyadic textual description and structural description for each couple’s experiences. In so doing, I observed if, when, and how participants referenced their spouses’ involvement in their own ACP either by using “we” language (Gardner, 2008) or otherwise including their spouses in their narratives. To be alert to possible bias, I also noted when the way I had phrased a question may have prompted a participant to reference a spouse, such as if I referred to the spouse or used plural language. Although I did slip occasionally, for the most part I employed singular language when posing questions. At the end of this phase, I had four dyadic textual descriptions and four dyadic structural descriptions.

**Composite analyses.** I reviewed the eight individual and four couple textual descriptions and summarized them in a single composite textual description. I then reviewed and synthesized the eight individual and four couple structural descriptions into a single composite structural description. In the final step of synthesis, these two composite summaries were integrated into one final textual-structural synthesis.

**Comparison with transcripts.** Once the data were synthesized, I returned to the raw transcripts to compare my summaries and observations with the participants' own descriptions of their experiences. To guard against interpretive bias (Ryan & Bernard, 2000), I searched for statements that were inconsistent with my observations and conclusions and, when found, amended my summary to incorporate these negative cases into my analysis.

**Card sorting exercise.** My original plan was to compare the results from the card sorting exercise within and across dyads by plotting the data in a grid and observing patterns of agreement and disagreement in what events were identified as influential to participants' ACP. This proved impossible because the card sorting exercise was carried out differently depending on how long ago the interviewee had completed an advance directive. Furthermore, participants struggled to prioritize or order the event cards, preferring instead to talk about each one and how it had made them reflect on the need to plan for the end of life. The two participants with mild cognitive impairment lost track of the task in the middle of the exercise and placed cards on the table that had either not occurred or were not influential to their ACP. In the end, the card exercise was a valuable elicitation tool that enriched the participants' narratives, but the selection and arrangement of the cards themselves did not yield usable data.

**Self-reflection.** Qualitative research requires the investigator to be self-reflective throughout the process and "bracket" her own assumptions in order to come to participants' narratives with an open mind (Starks & Trinidad, 2007). During both data collection and analysis, I documented the preconceptions that I discovered I had brought to the research project. Explicitly identifying these assumptions helped me to set them aside as I proceeded with the research.

## Chapter 7

### Qualitative Study: Results

#### Participants

I interviewed eight married participants, four husbands and four wives. The average interview duration was just under one hour (36-92 minutes). None of the interviewees were personally known to me. Both spouses of each couple were interviewed on the same day except for one husband and wife pair (Bob and Beth) who were interviewed a week apart. All but two interviews were conducted in participants' homes. One couple (Helen and Harold) was interviewed at the public library.

All the participants were white and ranged in age from 64 to 84. All of the couples had been married for more than 40 years. An overview of participants' characteristics and ACP histories is presented in Table 11. What follows is a brief profile of each couple. Husbands and wives have been given pseudonyms that begin with the same first letter. Non-essential facts that could potentially be used to identify participants have also been changed to preserve anonymity.

Table 11  
*Interviewee Characteristics*

	Age	Ed	SRH	# children	Year AD	Assisted by	With estate planning
Beth	70	MA	E	3	2013	Attorney	Yes
Bob	70	MA	E		2013	Attorney	Yes
Fran	84	SC	F/G	2	2016	Attorney	Yes
Fred	82	BA	F		2016	Attorney	Yes
Helen	64	SC	F	3	2003	Hospital Staff	No
Harold	65	HS	F/G		2011	Hospital Staff	No
Nancy	73	MA	G/VG	0	n/a	n/a	n/a
Ned	73	MA	VG		2006	Software	Yes

*Note.* Ed = education; SRH = self-reported health status; AD = advance directive; HS = high school; SC = some college; BA = bachelor's degree; MA = master's degree; E = excellent; VG = very good; G = good; F = fair.

**Beth and Bob.** Beth and Bob were both 70 years old, had graduate degrees, and had been married to one another for more than 40 years. Beth grew up with multiple siblings in a large extended family, whereas Bob was an only child. Both sets of parents died several years ago. They had three adult children and several grandchildren, none of whom lived close by. Both described their health as excellent. Beth previously worked in health care and later as an accountant. Bob had been employed as a computer programmer. In retirement, they each continued to work part-time. Beth and Bob completed their advance directives at the same time in 2013 along with executing wills and a trust. Neither had completed advance directives before, although they had executed wills when their children were young.

**Fran and Fred.** Fran, age 84, and Fred, age 82, had been married for almost 60 years. Fran attended some college and worked as a nurse before she retired. Fred earned a bachelor's degree and had a variety of jobs in different sales, service, and manufacturing fields. Both had been retired for more than a decade. Fred had worked part-time in retirement until poor health recently forced him to stop. Both had serious health issues, with Fred rating his health as fair and Fran rating hers as between fair and good. Fran also had mild cognitive impairment. All four of their parents had been deceased for a number of years. Fran had one sister who died a few years ago and Fred had no siblings. They had one living daughter who lived in another state, one daughter who had recently died of cancer, and four grandchildren. Fred completed his advance directive in 2016 when he and Fran updated their wills. It was unclear whether Fran had also completed an advance directive or just a new will. In the 1990s, they had both executed wills and Fran had signed a DNR at that time.

**Helen and Harold.** Helen, 64, and Harold, 65 had been married since they were both in their early 20s. They had three children and several grandchildren. Helen had just recently



completed her bachelor's degree and was looking for full-time employment. (Helen is listed as having some college in Table 11 because that was her educational attainment when she completed her advance directive.) Before she returned to school, Helen had worked in a variety of service jobs. Harold had a high school degree and worked in construction until he became physically unable and began receiving disability benefits. Helen described her health as fair, and Harold described his as between fair and good. Both of Harold's parents were deceased, his mother several decades earlier and his father about five years ago. Helen's mother was still alive and her father died more than twenty years ago. Helen grew up in a large family with multiple brothers and sisters, whereas Harold had only one sibling. Helen filled out her advance directive in 2003 before undergoing gall bladder surgery. She may have handwritten some instructions informally many years before that when she was having health problems. She also verbally expressed life-sustaining treatment wishes to her husband before going into emergency surgery during childbirth. Harold completed his advance directive before knee surgery in 2011. They had executed wills but not advance directives many decades earlier before their children were born.

**Nancy and Ned.** Ned and Nancy were both 73, had graduate degrees, and had been married to one another for over 50 years. They had no children. Before they both retired, Ned taught at a college and worked for a private sector research company. Nancy was a school teacher. They each had one sibling and several nieces and nephews. Both sets of parents had been deceased for more than a decade. Nancy had recently had a series of strokes that caused some physical and cognitive limitations. She rated her health as between good and very good. Ned also had serious health problems in the past few years, but rated his current health as very good. Although Ned had told me when he enrolled in the study that he and Nancy had engaged in ACP, it turned out that they had not yet completed or executed the current versions of their

advance care and estate planning documents. Ned had previously executed a will and advance directive in about 2006, but Nancy never signed her documents.

### **Advance Directives as Part of a Broader Planning Process**

Going into this study, I had conceived of advance directive completion as a singular act that was influenced by motivating factors and barriers specific to written ACP. However, participants spoke about completing their advance directives as one part of a more comprehensive end-of-life planning process. Motivations for and barriers to other types of planning besides ACP were often cited as relevant to participants' experiences leading up to and completing their advance directives. For some, advance directive completion was only ancillary to other types of end-of-life planning.

**Estate planning.** Three of the couples engaged in ACP and estate planning at the same time. Bob described doing an advance directive as “part of the package” that also included creating a trust. Beth said, “So we did a revocable trust. We did a will. And we did the advance directive. All at one time.” Fred too described ACP as part of their estate planning. “Okay, we called Legal Services and updated the wills and did directives for the hospital thing. And got it taken care of.” Fran conflated estate planning and ACP to the point of not being sure if she had completed a separate advance directive. She described the appointment of her daughter as her decision maker this way, “It’s in the will, how it’s documented. That she is sole, sole doing everything.” Ned was preparing his and Nancy’s advance directives and wills using the software package *Quicken Willmaker*. “Working on an advance directive occurred at the same time as working on a will.”

**Body disposition.** Some participants connected ACP with planning for body disposition after death. When I asked if there was anything else I should know about her experience with

ACP, Beth responded, “Well, we’re both going to be cremated and put in the VA cemetery.” Fran transitioned immediately from talking about appointing her daughter as her decision maker to describing her funeral and burial arrangements. “We have Creighton Funeral Home. And we’re going to be buried at the military cemetery. So that’s all taken care of.” In explaining the purpose of an advance directive, Harold added, “I mean, I’d rather, I don’t want anybody spending a whole lot of money when I die. Whatever is the cheapest way to dispose of me, the better.” For Helen, the connection between ACP and body disposition came from considering how her life-sustaining treatment choices might impact her options to donate her body to science. “Do I give my body to science? . . . It’s like all this comes into effect if you are on life support and you want to give your parts away.” Ned saw completing his advance care and estate planning documents as well as arranging for cremation as parts of a larger process of preparing for death. “And so it’s been really that much in my conscience that we need to be better prepared for the end.”

### **Exposure to ACP**

Prior research has shown that exposure to information about ACP is a necessary first step, but is not sufficient by itself to motivate older adults to complete advance directives. All the participants except Harold reported knowing about advance directives for a long time prior to engaging in end-of-life planning. Participants became familiar with advance directives through one or more of six channels: (1) hospital or doctor; (2) making decisions on behalf of a parent; (3) professional experience; (4) printed media; (5) attorney; and (6) spouse or family member. Several participants reported receiving information from multiple sources and at multiple instances.

Bob learned about advance directives from health care providers and the media, “You would see these brochures in the doctor’s office. You read about them in news magazines.” He described being asked about his advance directive by his doctor and before surgery. “It’s brought up when you go see doctors. ‘Do you have an advance directive?’ I’ve had a couple of operations. And you’re laying there getting ready to go into the operating room. ‘Do you have an advance directive?’” Although Bob did not complete his advance directive until several years after his surgeries, he thought that the hospital staff’s questions raised his awareness. “Don’t ask me that now! I’m coming out! [laughs]. But they ask about it. You start thinking about it, you know. They just plant a seed.” Beth attributed her familiarity with advance directives to working in a hospital as well as her personal experience making life-sustaining treatment decisions for her father at the end of his life. She also said that her physician asked her more than once whether she had an advance directive. Neither Beth nor Bob mentioned their spouse as being present or part of their exposure to ACP.

Fred thought that information about advance directives was “kind of always there, like in the senior paper that comes.” He also believed that he and his wife may have talked about advance directives with an attorney many years ago when they first did their wills. Before his wife had surgery, he remembered that “we went to that directive thing” at the hospital, although they did not complete their advance directives then. Fran did not mention attending this presentation nor the attorney, but rather credited her husband with telling her about advance directives. “Well, it was him, Fred, my husband. He told me about them. That’s how I know.” In contrast to Beth and Bob, Fred and Fran described a more dyadic process of learning about written ACP by either receiving the information at the same time or from a spouse.

Helen thought she learned about advance directives when she was hospitalized, possibly with the birth of one of her children. She was asked about advance directives “pretty much every time I went in the hospital.” She also became familiar with them when studying nursing, a career she did not ultimately pursue. Harold learned about advance directives before undergoing surgery, remembering that “the hospital pretty much required it, when I had my knees done.” He recalled going to “a presentation about the durable power of attorney that you had to attend as part of the hospital deal.” Like Bob and Beth, Helen and Harold described separate pathways to learning about ACP, indicating a more individualistic process. This is particularly interesting because Harold was present when Helen completed her advance directive before her surgery, but he did not cite this experience as raising his awareness.

Ned did not know how he first learned about advance directives, but had been aware of them for a long time. Nancy said, “Well, the living will I’ve heard from Ned. Other documents I think I heard from Ned’s family members, his sister.” Nancy’s exposure to ACP was from or through her husband, suggesting a dyadic process. Ned did not mention any particular source of information so it is not possible to categorize the process as individualistic or dyadic.

### **Motivations and Barriers**

**Motivations.** Participants described a range of experiences and circumstances that heightened their interest in and willingness to complete advance directives. Sometimes these were specific to ACP, but participants also talked about motivations for engaging in estate planning or end-of-life planning more generally as relevant to understanding why they eventually completed advance directives. Frequently, these experiences occurred many years before taking action and were, as Bob described, “just these things which accumulate that leads you to start thinking along the lines of what you should do.” Motivating factors included growing older,

health problems, caring for parents and making end-of-life decisions on their behalf, witnessing others' end-of-life experiences, and problems with handling the estates of others.

**Aging.** Bob and Beth mentioned aging as a motivating factor for their end-of-life planning. Bob said, "You get older, you start thinking more about these things." Beth said something similar, "When you get older, you think about it. Not just when we turned 65, but aging in general. Knock on wood, our health is both very good. . . But, yeah, it's just you know, what's going to happen?" Bob contrasted his current self with his younger one. "Just being young. I don't need that. . . . And pretty soon you stop thinking that way. Because I can't think of a reason why you wouldn't get one now at my age."

In addition to chronological age, life events led Bob to be more aware of his own aging and to think more seriously about end-of-life planning. His and his wife's retirements signaled a shift toward older age. "I retired, she retired. So this is a milestone in your life, right? . . . And you realize that, oh! I'm in this part of my cycle. . . . I'm way along. It's getting to be fall. So, if it's getting to be fall, I've got to take some responsibilities now for winter, right? And the end of this cycle. So that's when you start thinking about these things more, right?" The birth of his first grandchild also made Bob realize that he was getting closer to the end of life. "When you have your first grandchild, you realize that you've completed your mission, right? You've passed on – you've had your children. Now they've had children. . . . So they're at the beginning of their cycle, well a little further along but they're at a point in their cycle, you going towards the end of your cycle. So you want to help them prepare for your end of cycle." The deaths of celebrities from his youth prompted him to prepare for his own death. "It's every day the people who were the entertainers, the singers that you grew up with, they all pass eventually. . . . So the longer you

live the longer you know about this cycle, and you want to prepare for this cycle and just be part of it. And accept it.”

**Health problems.** Surgery, particularly if it involved general anesthesia, caused some participants to confront their mortality and made end-of-life planning seem more relevant. Bob reflected, “You go under anesthesia and you start thinking about what if I don’t come out? Right? So that was just some things that just, oh! And when I get the time, you know, we’ll let this bubble.” Surgery also reminded Bob that he and his wife were “no longer superman and superwoman. Right? You say oh crap, I guess I’m not superman [laughs]. What do you mean I got to have this thing fixed? Oh, okay. So all of a sudden you are starting to see that in your cycle your body is changing. Not always for the better, right? You’re just getting old.” Both Helen and Harold also spoke about surgery as making them face their mortality. Helen said, “And because I also have problems with anesthesia and don’t come out of it well, and have allergies to some of those things, there’s no reason not to make a directive. That’s get real time.” Harold explained, “When you go in surgery the possibility of your demise exists.”

In contrast to surgery, two participants described the motivational effects of emergency hospitalization but noted they were only temporary. Nancy recalled, “Well you know, I just, once I got out of the hospital and felt good again, it’s gone! I wasn’t thinking about those things anymore. They were just something in the future.” Helen made a similar observation about why her husband had not completed an advance directive after an emergency hospitalization. “I truly believe that you don’t do anything until you have to. So when you’re better you forget about it.”

Both Ned and Nancy cited their own declining health as making them more aware of the need to plan for the end of life, but not enough to prompt action yet. Nancy said, “Well, it [declining health] made me think more and more often and more intensely about doing a will.

Getting a will done. But I haven't done anything about it yet, really. Very little." Talking about his parents' deaths, Ned reflected, "I'm sure that those events, those life events, have to have some influence on one's realization that you better sort of get yourself prepared. As well as my own health."

Helen spoke about several near death experiences, including during childbirth, as motivating her to document her treatment preferences to be sure that her wishes would be carried out. "Because I had a reality check, more than once. You know it's like I made medical decisions or had a near death, this here with me having nine months carrying my son and verbally handing my wishes to my husband, you should know that I told him to save the baby first." After both mother and baby had survived, Harold told her that he would have saved her life against her expressed wishes. "And he said, after the fact, he said I would have saved you first. So that is – OKAY, AND THAT MADE YOU FEEL LIKE YOU WANTED TO WRITE YOUR WISHES DOWN?<sup>2</sup> Yeah! Definitely, because I was old enough to go heaven, and so is a little baby but a little baby doesn't have a chance to live."

Spouses' physical and cognitive health problems were influential for two participants. For Fred, his wife's diagnosis of mild dementia two years earlier made updating their end-of-life planning documents more imperative. "Well, she was diagnosed with not major, but minor dementia. . . . kind of just felt like it needed to be done." Ned observed that, in addition to his own health, his wife's declining health increased his sense of urgency. "I'm sure that Nancy's health undoubtedly has had some influence on this. She's unfortunately had several strokes. . . . Well, it makes it much more imperative that we are better prepared for the inevitable."

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<sup>2</sup> Capitalized portion of quote refers to interviewer question.



*Parental caregiving and making decisions for parents.* Experiences with parents and parents-in-law were frequently mentioned as motivating end-of-life planning. These experiences included providing care and support and making end-of-life medical treatment decisions on parents' behalf.

Beth and Bob cited the financial and caregiving support they provided to her father and his mother as motivating them to plan for her own long-term care and end-of-life care needs. Beth said, "Probably what motivated us more than anything is we financially took care of my father. . . . And then his [Bob's] mother – he was an only child – lived with us for nine years. And we took care of her." Bob explained, "And we did things for grandpa [Beth's father], to make him as independent as possible when he got ready to move off the farm. We got a place in town for him." He also described caring for his mother, "When she moved in with us, she suffered from depression. And there was issues with that. So we had to make medical decisions, go to a psychiatrist, do this, put her on medications, that type of thing. . . . One time when she was living with us, she broke her hip. So we had to work on that with her."

Both Beth and Bob were also involved in making life-sustaining treatment decisions on behalf of a parent at the end of his life. Beth recalled making the decision with her siblings, "We all decided Dad did not want to be on life support. I mean he made that quite clear." She also described Bob's decision on behalf of his mother. "And my husband was an only child, and when she had her massive stroke . . . And so that we had to both make – he had to make the decision. The doctor called him to do life support or not." Beth was confident that she and her siblings had made the right decision for their father. "My father did not want to go to a nursing home. And my father did *not* want to be hooked up to anything. And so I had to be the one that said no, he doesn't want any life-sustaining measures. And I felt very comfortable doing that

because we all knew he didn't want to." Bob struggled more than his wife with his choice to withhold life-sustaining treatment from his mother in part because, as an only child, the responsibility fell on his shoulders alone. "You've got to make that decision, right? And that decision on my part was, yeah, just, you know, she's not going to want to do that. But that's not an easy decision to make. Especially if you're an only child. There's no way, really, to talk about it, except to your wife." Bob hoped that by completing an advance directive he could make dealing with a similar situation easier for his children. "But just making these type of decisions, it led us, led me to believe that you need to do this so that your sons don't have to be worried about that. It's done, it's made, the decision's made. And they don't have to labor over it."

Helen and her siblings made the decision to remove their father from life support. "He did not have one of these health care setups. So my mom wouldn't do it. So us girls had to say whether we keep him on life support. What we do. And that was my aha moment that you need to plan ahead of time." Even though Helen called it her "aha moment," she did not complete her own advance directive until many years later. Like Bob, Helen struggled with the decision. "We predicted how he would feel, but we didn't know. And we felt, honestly, like we had signed his death warrant. Because he was dying, but there's always a hope that they might come back. And we felt like executioners." Also similar to Bob, by completing an advance directive Helen hoped to spare her family the guilt that she experienced withdrawing life-sustaining treatment from her father. "So I have to assure them, it's okay to pull the plug. . . . Please! Pull the plug. Not just it's okay. Please! Pull the plug. So they've got the pat on the back to pull the plug and not feel guilty about it. I felt guilty about the decision I had to make about my dad."

Soon after Helen's father died, Harold's mother went into the hospital. She recalled, "And the minute my dad died, his mother was in the hospital the next month. And so we had to

start this all over again. . . So we had one upon another where there should be something taken care of. Do you want your body to go to science? Do you want this? Do you want life support?"

Although Harold's mother did not have an advance directive, she had verbally expressed her readiness to die to her husband and other family members. Harold described his role as supporting his father who made the decision to remove life support. "And I just told Father, if she wants to go, it's okay with me. I knew he had the final say. And I think he wanted somebody to collaborate with him on it. I don't think he wanted the full power."

Nancy and Ned were not directly involved with caring for their parents because they each had a sibling who lived closer and took on the responsibility. Ned nevertheless thought that "dealing with our aging parents undoubtedly had some influence" but it "wasn't a major influence." Their parents' aging and deaths "have some influence on one's realization that you better sort of get yourself prepared."

***Witnessing others.*** The three participants with health-related professional training or backgrounds mentioned school- or work-related experiences that shaped their thinking about their own ACP. Helen recalled being in nursing school, "I think these [advance directives] are important because I had been in an Alzheimer's unit. . . . And I'm going they don't know to sign these things ahead of time. What do you do when the brain's gone?" Fran explained why she signed a DNR. "Working as a nurse you've seen how some just drag along, and they just, you're not going to make it, and they just poke 'em and oxygen and everything, and I didn't want it." Beth talked about how her experiences in health care influenced her preferences not to receive life-sustaining treatment, "I guess it's just working in a hospital. And there's a reason to be there, and you have cancer it's probably going to be a while, but I just hope that they make me comfortable and don't try to prolong my life."

Bob spoke about people he and Beth had known who went into nursing homes as motivating him to engaging in end-of-life planning. “Now we both have had friends that have moved into nursing homes. . . . You want to, before you have to go into a nursing home, get things ready. Get things so your, the people who are responsible, your sons, daughters, don’t have to.”

***Estates and estate planning.*** Negative experiences involving the estates of others motivated some to make sure their own estate planning documents were in order and hopefully avoid legal difficulties for their survivors. Fran spoke about how complications handling her parents’ estates made her want to make it easier on those who will be handling her affairs. “When my parents died we went through a lot of stuff with probate and trying to unlock the key at the bank to get their stuff. And it just, I just didn’t want anybody else to have to do what we went through. And selling her home and everything. It just, I just wanted it to be easier.” Ned recalled preparing his mother’s house for sale after her death. “My sister and I and Nancy spent a month in the house . . . getting it ready to sell. And learned that Mother had not processed her will. . . . So we had to go through a legal process. We had to hire a lawyer and go through that process.” He observed, “I know that if one dies without a will, it can make the heirs go through a lot of legal problems.”

There was also a recognition that poor planning could result in conflicts among surviving family members. Although he did not anticipate his relatives would bicker, Ned said about dying without a will, “In some families that can be a real problem, fighting over property and inheritance and goods.” Bob talked about handling the estate of an uncle, “Whatever you do, was either all wrong or half wrong. . . . So we both felt, at least I did anyway, now if you get it and you put it down how you want it, then nobody has a say. . . . And then there will be no creation

of hard feelings within an extended family.” Beth explained why she and Bob felt the need to complete their estate planning. “My profession, you deal with an awful lot of divorced families. Your stuff, my stuff, our stuff. . . . And so we just decided how we were going to divide it up.”

**Barriers.** Interviewees identified reasons why they had not engaged in end-of-life planning earlier or, in the case of Ned and Nancy, why they had not yet executed their most recent documents. The most commonly mentioned barrier was discomfort thinking about death. Other reasons included inertia or lack of a sense of urgency and legal costs, particularly when ACP was tied to estate planning.

**Death avoidance.** The most common reason that participants gave for procrastinating completing an advance directive was not wanting to think about illness or death. When he was younger, Bob did not want to admit he needed an advance directive. “I guess when I was younger, eh, I don’t need that. I don’t need a death wish.” Ned observed that written ACP required accepting one’s own mortality. “But it’s the kind of thing that doing it, I guess we’re sort of saying okay, yes, I will die one of these days. Okay, I’ll admit that, yes. I guess that’s probably why we don’t want to fill one out.” His wife Nancy displayed a reluctance to face the possibility of death several times during our interview. When explaining why her husband’s hospitalization did not lead her to think about end-of-life planning, she said, “I didn’t think about it because he will get better and he’ll be fine.” Although she acknowledged that she would have to “rethink everything” if her husband died, she said, “I’m just going to go along and keep living as I am doing until I can’t anymore. That’s it.” Harold observed that completing an advance directive is “an easy thing to postpone” because “people don’t like to think of their mortality. People aren’t comfortable with that. That’s why I think that. I’m not sure that if, until today, if I hadn’t had surgery and didn’t have to fill out that durable power of attorney, whether I would

have done it.” His wife put it the most bluntly, “And when you look at that directive, that’s death.”

***Inertia.*** A lack of desire, interest, or sense of urgency was another reason given for not engaging in end-of-life planning earlier. Bob remembered how he felt about advance directives when he was younger, “I didn’t want to think I needed one. So I said no, I’ll do it later. I got time.” He also thought that the delay was caused in part because “there was nobody there to kick me in the butt and tell me, you know, you really ought to do it.” Beth “just never took the time” before to do her advance directive. Nancy observed that she and her husband “just never got around to it” and admitted that “it’s something I don’t want to deal with particularly.” Her reluctance to engage in end-of-life planning seemed to spring in part from a lack of confidence in her ability to make decisions. She explained, “Well, the fact that I just don’t know my stuff well enough, my history well enough to say yes or no about things. . . . You know, if things come up I don’t know the answer to, I just [waves her hand] forget it.”

***Legal costs.*** The cost of legal services was another perceived barrier, particularly when ACP was linked to estate planning. Fran explained why she and her husband waited to update their end-of-life planning documents, “Because he [Fred] didn’t know that you could do it for free. Because the first lawyer cost us over \$300 to have it done. And he said we can’t afford \$300 again. So when he found this one, we jumped in and did it.” Helen cited legal expenses for the reason she has not updated her will, but recognized that she could use more affordable programs available through the internet. “And you know it takes money, but you can also do these on-line things. So I’m saying well, get your rear in gear and get on-line and do something.” Her husband also did not feel like they could afford legal services. “But at this moment we’re on

a very fixed income. . . . Right now, financially, to hire an attorney, I don't even know what the cost is."

**Summary of motivations and barriers.** In summary, participants described their own aging, their own and their spouse's health problems, caring for parents and in-laws, making end-of-life medical decisions on behalf of parents, witnessing the end-of-life experiences of others, and negative experiences with handling the estates of others as motivating them to eventually engage in their own end-of-life planning. Commonly named barriers were reluctance to face one's own mortality, inertia, and legal costs. Interviewees were influenced both positively and negatively by events and circumstances in their own lives and their spouses' lives, such as declines in health and end-of-life decision-making on behalf of parents. Other influential factors were jointly experienced, including financial barriers to accessing legal help and shared caregiving responsibilities.

### **Triggers**

The motivating factors described in the previous section made participants more aware of the need to plan for the end of life. Triggering events or circumstances finally prompted participants to take concrete preparatory steps toward end-of-life planning. Moving to a new state and the resulting distance from family prompted Beth and Bob to engage in both ACP and estate planning. Beth saw herself as taking the initiative to find and contact an attorney about preparing these documents for herself and her husband. Although triggered by the move, Beth thought they would have done their end-of-life planning anyway because of the geographical distance from their children. "Well, we moved out here and we had to make – because well even if we wouldn't have moved here – our children don't live around us. And we needed for them to have something to make decisions." Similarly, the geographic distance from children was

mentioned by Bob. “We did know that they were scattered geographically. . . . We wanted them to know where things were and who to contact. Since they're not gonna, you know, they're not gonna be living with us.”

Their daughter's death and Fred's hospitalization prompted Fran to initiate their end-of-life planning process by asking Fred if he was satisfied with their wills. Fran remembered, “Are you happy, I asked him, are you happy with the will? And he said no, and I said that neither am I.” Her sense of urgency came from Fred's hospitalization. “Well, you don't realize how old you are and how well you feel until something like this happens. You go, my gosh, I'm in my 80s! We've got to do something with it.” Their main concern was that Fred and their daughter's surviving spouse (the father of three of their grandchildren) did not get along. Fred explained, “We ran into dippy dummy son-in-law, and that needed to be changed. And we made Jessica our executrix. And she gets everything. So it needed to be done.” Fran agreed, “Well, the reason we – my husband has never liked, my daughter who died, her husband. . . . So when we redid our will, we cut that whole bunch out.” For Fred, his daughter's death seemed to have been the primary triggering event. Fred described his sense of incompleteness after her death, “Well, it was like we hadn't finished. . . . And she got cancer and asked me if she could come here to die. And I said yeah, you're my daughter. . . . It was like we hadn't finished. And if we had written something down or had the thing to show us, that it would be taken care of.” Although Fran initiated the process, it was Fred who called the Senior Center for information about affordable legal services and made the appointment with a Legal Aid attorney. He did not believe his wife would have found or reached out to the attorney on her own. “She'd never go and talk to anybody. . . . I talk to people. I stop on the street and talk to people.”



For Harold and Helen, going into the hospital for non-emergency surgery led each to complete an advance directive at different times. Helen did hers in 2003 when “I had a gall bladder that needed to come out. And that’s when I did that first directive.” Harold completed his in 2011 because “the hospital pretty much required it. When I had my knees done.” Neither considered doing an advance directive at the same time as the other. For Harold, it just “never occurred to me” because he was “going really good” at the time of his wife’s surgery. Helen did not complete an advance directive when her husband did because she had already done one. Because both Helen and Harold completed their forms only hours or days before surgery, there was little preparation done by either. They were relatively passive in the process, responding to hospital staff’s requests that they complete the forms.

At the time of the interview, Ned was in the process of preparing end-of-life planning documents for both himself and Nancy using a self-help computer program. “I did it with an electronic application on the computer knowing that we should have wills and advance directives and all of that.” When asked directly, Ned denied that there was any particular event or circumstance that prompted him to begin drafting these new documents. “It wasn’t any particular event. It was just knowing that I should update these things.” However, over the course of the interview he made references to some possible triggers. One was the death of a niece. “My sister’s oldest child died. She had been in my original will. So obviously I would need to take her name out. So I just thought things needed to be updated.” His and Nancy’s recent move to a new state also seemed to have caused him to revisit the documents in order to make sure they complied with state legal requirements.

Ned had not succeeded in convincing Nancy to participate in the planning process. Nancy said, “Ned has mentioned that we ought to get down seriously and talk about those things.”

However, Nancy is not interested and would prefer if Ned could do her planning for her. “It isn’t that I don’t want to do it. This sounds silly, but if he could do it, I’d sign it. You know, I’d just, that’s the kind of thing that, you know, it’s something I don’t want to deal with particularly.” As her caregiver, Ned has taken over responsibility for making decisions Nancy no longer feels able to handle after her strokes. “Well, he’s a caregiver to me. He has the ability to think through problems or decisions or ideas that I don’t know about anymore.” Nancy’s reluctance to participate with her husband in drafting and completing their end-of-life planning documents seems to have hampered both of their preparations. Ned explained, “Well, they sit there electronically. I printed out a couple of things. I think mostly what I printed out are forms in reference to Nancy so we can sit down and go through those, which we haven’t done. Mine are still just, I haven’t printed out mine yet. I mean I could, I just haven’t.”

**Summary of triggers and preparations.** Preparatory actions included finding assistance to draft planning documents or drafting them for oneself. Events such as a move to a new state, the death of a family member, and hospitalization triggered these concrete steps toward end-of-life planning. With the exception of Harold and Helen, spouses were prompted to take action by the same triggering events which were either common fate occurrences (e.g., a move or death of a family member) or perceived as impacting both spouses (e.g., the hospitalization of one spouse). Spouses could help one another, as with Fran and Fred, or be a hindrance to moving forward, as with Nancy and Ned. In contrast to the other couples, Harold and Helen described a more individualistic process with separate triggers and little identification with the other’s need to engage in ACP. Neither of them took active steps to prepare, but rather reacted to the promptings of others.

## **Engaging in End-of-Life Planning**

**Outside assistance.** Each couple who successfully completed end-of-life planning was helped by either an attorney or health care provider. A private attorney prepared all the documents for Bob and Beth and assisted them with executing them. “We did it with an attorney,” Beth explained. Bob said, “We were down in his office. And we filled them out. He came back and looked them over. And then we finalized it.” He was happy to do his advance directive along with their estate planning. “It was available when we did trusts. And it was just, yeah, let's do it. This is a good time to do it. We got the guy here, part of the package. Let's do it!”

A Legal Aid attorney helped Fred and Fran with their planning documents. Fred remembered, “We called Legal Services and updated the wills and did the directives for the hospital thing. And got it taken care of.” However, it was unclear if Fran also signed an advance directive or just a will. Fran only remembered signing the will, whereas Fred said about her advance directive, “I think she did. We both did ‘em together.”

Helen and Harold were helped by hospital staff before each underwent surgery. Their descriptions of this assistance were similar, including being asked if they had an advance directive, being provided a form, and then having the document notarized by office staff. Helen filled her form out in the waiting room. “I had time, and in fact I went in to have the surgery and it was supposed to be in the morning. And the doctor kept adding people after people. . . . And then I’d already had plenty of time sitting there all day to make this out.” Harold completed his advance directive at home and brought it with him on the day of his surgery. “I had made a prior visit to the hospital to check the anesthesiologist and all the other people, all the other sundry

events that go into having your knees replaced. And we did that, and part of it was we needed to fill this out. So I filled out the form. I gave it to them. They notarized it.”

In contrast, Ned was updating his and Nancy’s advance directives and estate planning documents without outside assistance and little involvement from his wife. Talking about both his earlier and current end-of-life planning, Ned said, “Well, I went through and, I think I did most of hers and then she sat down with me and answered a few questions. But I’m not sure why we never did finish the process on hers. And again, with this newer version, I’ve got an initial, I’ve got started but we need to sit down and work at it together.” In addition to Nancy’s resistance, part of the delay may be caused by Ned trying to engage in end-of-life planning without outside assistance. Ned cited his lack of knowledge about state legal requirements as one reason for not finishing. “What I have to find out now is what the legal requirements are here. . . Does it need to be notarized? Does it need to be recorded?” I gave him a state-specific handout about advance directives after the interview.

**Decision-making process.** Each couple who had completed their end-of-life planning described a different decision-making process, and in each case these descriptions varied between husbands and wives. Although they “pretty much” agreed that they “didn’t want to be a vegetable,” Beth did not feel it necessary that she and Bob have similar instructions in their advance directives. Bob, in contrast, described a more collaborative decision-making process. “Well, as with everything, we sort of agree on our things. And at the end of the day, if you’re a little bit apart, it’s not going to make a difference. You compromise and you say yes, this is where we’re going.” He felt it was important that they come to a consensus, but that after such a long marriage it did not require much discussion and was not difficult to reach. Neither of them discussed their preferences or consulted with their children beforehand.

Fred described a coordinated but independent decision-making process. “She’s on her own and I’m on my own, and we do it together.” Fran described Fred as taking the lead and herself as deferring to Fred’s wish to disinherit the children of their deceased daughter. “I didn’t have any qualms about him marking out the previous relatives. So I didn’t fuss about that. That was his job, and I didn’t mind.” She was not concerned that their life-sustaining treatment preferences differed in that she had a DNR and Fred did not. Like Beth and Bob, they did not talk to their daughter ahead of time about their decisions.

Helen did not mention discussing her choices with Harold when she completed her advance directive. When Harold filled out his advance directive, he discussed his choices with Helen to be sure she was comfortable with them as his proxy. “I felt it was basically my decision but I wanted her input because she was going to be the one who had to carry it out. And I didn’t want her, I didn’t want to have something that was so – something she couldn’t carry out in her own mind.” Neither Helen nor Harold consulted with their children about their decisions before completing their advance directives.

**Summary.** The three couples who succeeded in engaging in end-of-life planning received external assistance, whereas the one couple who had not was trying to proceed without outside help. Those who were helped by attorneys completed their end-of-life planning documents at the same time as their spouses. In contrast, the one couple who was helped by hospital staff engaged in ACP separately. Most participants characterized their decisions about end-of-life care as primarily their own. Some were concerned about their spouses’ opinions of their preferences or thought it important that they engage in joint decision making while others did not express these concerns. None of the participants talked with their children about their decisions in advance.

## **Sharing, Safekeeping, and Updating**

**Accessibility.** To make sure surrogates would have access to the planning documents if needed, it was common for participants to provide them with copies. Beth and Bob gave copies to each of their children who were named as health care proxies. Fred and Fran gave a copy to their daughter whom they named as executor and proxy. After Ned completed an advance directive and will a number of years ago, he sent a copy to his sister who was named as an alternate proxy after his wife. Only Harold and Helen did not seem to have shared their advance directives with their children or others. Helen reported meeting with resistance from her children when she attempted to talk about end-of-life issues. “The first words out of their mouths are – especially my oldest son – are, ‘Oh Mom, you’re going to live forever.’ And I want to say will you get real?”

Bob planned to also give a copy to his physician. “Well, it’s upstairs. And I know, it’s been on my mind, the thing I have to do that I found that I could do, I need to take one to the doctor. And I haven’t done that. I just haven’t got around to it.” He thought that by giving a copy to his doctor, his advance directive would be available if he were to go into the hospital. “I need to have one there because if I have one there it’s probably good with the hospital.”

**Safekeeping.** In addition to being accessible if needed, safekeeping was another concern. Bob was considering filing a copy in the courthouse. “The other thing I can do is, like all papers, you can take it down to the courthouse and put it in the courthouse.” Having a copy on public record would ensure that his advance directive would not get lost or destroyed. “So if we have it in the courthouse, then it’s there and it’s good. If it’s somewhere else, it could get lost or it could get burned, or whatever.” Loss was in fact a problem for a couple of participants. When Helen looked for her advance directive in preparation for our interview, she found that she no longer

had a signed copy. Fred was also unsure of where his planning documents were. “Mother knows where hers is. She always knows where everything is. And Fred loses stuff. There’s a will around here somewhere.”

**Updating.** End-of-life planning can become outdated as circumstances change. Moving to a new state with different legal requirements and the death of a will beneficiary rendered Ned’s 2006 planning documents out-of-date. Fran and Fred felt like they needed to update their wills after the death of their daughter. When this occurs, older adults may find themselves returning to earlier steps in the planning process.

## **Chapter 8**

### **Discussion**

This research project challenged the dominant approach of conceiving of and studying ACP as largely an individual behavior. I argued at the outset that current scholarship and practice often fail to recognize important social influences on older adults' decisions to engage in ACP, particularly by those who are married. I conducted two studies – one quantitative and one qualitative – to test this proposition and develop a relational model of advance directive completion by older married persons. The quantitative study demonstrated that taking a dyadic approach to understanding why some older married adults have advance directives while others do not is both feasible and informative. Through interviews with older couples who had engaged in end-of-life planning, I gained a deeper understanding of the personal and spousal events and circumstances that motivated, delayed, or triggered advance directive completion. I also explored to what extent the processes leading up to advance directive completion by these husbands and wives were independent or interdependent. In this chapter, I integrate and summarize the main findings from the quantitative and qualitative studies. I then apply these findings to evaluate and modify the proposed relational model.

#### **Personal and Spousal Factors Influencing ACP**

**Age.** Consistent with previous research, the quantitative data indicated that one's own age was positively associated with advance directive completion. As I had predicted, spousal age was also positively related to advance directive possession above and beyond the individual effects. This is the first study to demonstrate that advance directive completion is a function of both spouses' ages, not just the age of the person completing the form.



The data from the qualitative study shed additional light on how personal and spousal age may motivate end-of-life planning. Several participants spoke of how chronological age and age-related events in their own lives and the lives of their spouses raised their awareness of potential health problems and their own mortality. Because spouses age together, their shared experiences growing older likely influence their perceptions of their own and one another's vulnerabilities and needs. This awareness makes end-of-life planning seem more relevant and more urgent.

**Education.** Also consistent with previous studies, the quantitative data showed that those with higher education were more likely to have advance directives. As predicted, spousal educational attainment was also positively associated with advance directive possession above and beyond the individual effects. Again, this is the first study to show that advance directive completion is a function of the couple's education rather than just the individual's educational attainment.

It is possible that one spouse with higher education can compensate for the other spouse's lower level of educational attainment by passing on information about ACP to their spouse. Illustrating this possibility, two women in the qualitative study identified their husbands as a source of information about advance directives. One of the women had the same level of education as her husband and the other had less education. Education is also linked to lifetime earnings and financial management. Those couples who have been able to accrue significant assets due to the higher education of one or both spouses may be more likely to engage in estate planning which may in turn prompt ACP.

**Health status.** Contrary to my predictions and some prior research, personal self-reported health status was not significantly associated with advance directive possession in the quantitative study. Although I anticipated finding a positive relationship between spouse's poorer

health and advance directive completion, the data showed that those whose spouses were in poorer health were less likely to have advance directives.

I propose a few possible explanations for why spousal poorer health may reduce the likelihood of having an advance directive. Because completing an advance directive often involves naming a health care proxy, those whose spouses are ill may be uncertain about whom to appoint. Admitting that a spouse may not be alive or well enough in the future to serve as one's health care proxy could be too emotionally difficult, causing some to postpone making the decision. Those with significant caregiving responsibilities may be focused on meeting the short-term needs of their spouses and think less about their own long-term planning. This is the first study to demonstrate how spousal health may be associated with ACP, and the surprising direction of the observed relationship merits further investigation.

The use of a global measurement of health may also be problematic. The qualitative data illustrated how different aspects and types of declining health may motivate or discourage ACP. Gradual age-related declines in physical health made some participants think more seriously about engaging in ACP. A spouse's cognitive impairment gave some a greater sense of urgency about getting their end-of-life planning in order. However, Nancy's strokes contributed to her reluctance to engage in end-of-life planning, which also stymied her husband's planning. Non-emergency health conditions requiring surgery led to contemplation of the possibility of not waking up from anesthesia. In contrast, emergency health situations had only temporary effects that went away once participants recovered. These findings point to the potential for differential influences of various types of health conditions and events that is not captured with a single global measure such as self-reported health status.

**Prior hospitalization and/or outpatient surgery.** The quantitative data showed that men's prior hospitalization and/or outpatient surgery increased their likelihood of completing an advance directive. However, there was no significant association between women's hospitalization and their own advance directive completion. This is the first study to find gender differences in the relationship between hospitalization and ACP.

This is also the first study to observe partner effects of hospitalization. Women whose husbands had been hospitalized or underwent outpatient surgery were more likely to have advance directives, but there were no significant partner effects of women's hospitalization and/or outpatient surgery. These findings are consistent with my prediction that men's health events would have a greater effect on both their own and their spouses' ACP than women's health events.

The qualitative data provided some insights into how hospitalization and surgery can influence end-of-life planning and some possible reasons for gender differences. Going into the hospital for pre-scheduled surgery was frequently cited as a source of information about advance directives. Consistent with PSDA mandates, participants reported being asked about their advance directive status, attending presentations on ACP sponsored by local hospitals, and receiving assistance from hospital staff with completing advance directive forms. Pre-scheduled surgery involving anesthesia led several participants to reflect on their own mortality which made end-of-life planning seem more relevant. In contrast, emergency hospitalization was described as only temporarily increasing motivation to plan for the end of life.

Comparing the experiences of the two couples who identified hospitalization as a triggering event (rather than just a motivational factor) provides some clues about possible reasons for the gender differences observed in the quantitative data. Fred and Fran engaged in

end-of-life planning in part because Fred's hospitalization gave Fran a sense of urgency to make sure their wills were current. Fred's hospitalization therefore triggered planning actions for both husband and wife. In contrast, Harold was not motivated to engage in ACP along with his wife when she completed her advance directive before her surgery. He focused on how he was feeling at the time and did not view her health problems as requiring joint planning.

One major difference between these two cases is that Fran and Fred engaged in both financial and health planning with the help of an attorney, while Helen and Harold only completed advance directives in the hospital. However, these two examples also suggest possible differences in how men and women interpret spousal health events, with women tending to view spousal health as affecting both of them, whereas men may have a more individualistic perspective. This is consistent with prior research showing that older women tend to be more sensitive than older men to the physical, cognitive, and emotional states of their spouses (Berg & Upchurch, 2007).

**Regular health care provider.** In the quantitative study, women who had regular health care providers were more likely to have advance directives. However, there were no significant actor effects for men's regular health care provider status. One potential explanation for these gender differences is the types of health care providers used by men and women. While 85% of the women in the sample who had regular health care provider reported going to a doctor or HMO (as opposed to using a clinic or other type of provider), only 80% of men with regular health care providers listed a doctor or HMO as their regular source of care. It is possible that those who use clinics do not establish ongoing relationships with the same health providers that would lead end-of-life discussion and planning.

Some participants in the qualitative study mentioned being asked about advance directives by their primary physicians, but the interview data do not shed any light on possible reasons for these gender differences.

**Other personal and spousal factors.** Participants in the qualitative study identified additional personal and spousal factors that influenced their decisions to engage in end-of-life planning either as motivations, barriers, or triggers. In particular, caregiving for parents and parents-in-law, making life-sustaining treatment decisions on behalf of parents, witnessing the end-of-life experiences of others, negative experiences with the handling of estates, the deaths of close family members, and moving to a new state encouraged participants to get their own planning documents in order. Reluctance to acknowledge death, lack of a sense of urgency, and financial constraints were cited as barriers to end-of-life planning. Many of these factors have also been identified as influential in prior studies which have found that greater financial resources, experiencing a loved one's death, and making end-of-life decisions on behalf of another are positively associated with advance directive completion, whereas death anxiety or avoidance and feeling too healthy or too young to need an advance directive are reasons people do not engage in ACP.

### **Evaluating the Relational Model of End-of-life Planning**

Both the quantitative and qualitative data provide general support for the usefulness of the proposed relational model for conceptualizing how older married couples engage in ACP.

**Contextual Interdependence.** The quantitative data showed that husbands and wives tend to be influenced by their own and one another's individual (age, education, health status) and organizational (interactions with health care providers) factors, albeit with gender differences. The importance of spousal-, interpersonal-, organizational-, and policy-level

contextual influences was also evident in the qualitative data. Participants described learning about advance directives from their spouses, other family members, health care providers, attorneys, and the media. Several reported being repeatedly asked about and encouraged to engage in ACP by doctors or hospital staff. The motivations and triggers for end-of-life planning described by participants included personal factors such as a growing awareness of aging and mortality, marital factors such as a spouse's hospitalization or health, and interpersonal factors such as the illness and death of parents and in-laws. Likewise, barriers included death avoidance (personal factor), spousal reluctance (marital factor), and cost (organizational factor).

**Process Interdependence.** Participants in the qualitative study described a gradual process of becoming more aware of ACP, growing more interested in end-of-life planning, overcoming obstacles, and finally taking concrete steps that led to completion of advance directives. There was also a post-action maintenance phase involving safeguarding, sharing, and keeping their planning documents current.

For the husbands and wives in the qualitative study, these steps were frequently intertwined, although with variation in the degree of interrelatedness across couples. For some, learning about ACP was primarily an individual process while others gained knowledge along with, from, or through their spouses in a more dyadic process. Motivators ranged from the growing realization of one's own aging, described as being experienced at the personal level, to parental caregiving that was jointly experienced. With one exception, spouses were prompted to take preparatory action by triggering events that were either common fate occurrences (e.g., a move or the death of a family member) or perceived as impacting both spouses (e.g., the hospitalization of one spouse). Spouses could encourage one another and compensate for one

another's limitations or hinder progress by refusing to engage. One couple's experience differed from the others, involving a more individualistic process and little preparation.

**Model modifications.** There were some elements of the written ACP process described by participants that did not fit the proposed relational TTM well. Becoming more aware of advance directives was a gradual process involving multiple instances of exposure from multiple sources. This could occur before, during, or subsequent to the motivating events or circumstances. Participants did not necessarily actively contemplate engaging in ACP but rather experienced a series of life events and circumstances that made end-of-life planning seem more relevant. I would describe this as priming rather than contemplation. Priming is a concept borrowed from the psychological literature that describes how prior exposure to information or experiences shapes one's interpretation of and response to a given situation (Herr, 1986).

Advance directives were just one part of a more comprehensive process of end-of-life planning. ACP, estate planning, and funeral or body disposition arrangements were frequently completed at the same time or understood as linked. The motivations for and barriers to estate planning were often cited as influences on participants' ACP. This suggests that any model seeking to predict advance directive completion should be expanded to include potential predictors of other types of end-of-life planning, particularly estate planning and body disposition.

The decisional balance aspect of the TTM did not quite match the process described by interviewees. The TTM postulates that change is a function of a shift in the perceived relative advantages and disadvantages of a contemplated behavior (Prochaska et al., 1994). This calculation involves considerations of gains and losses for both the self and significant others, self-approval or self-disapproval, and the positive or negative judgments of others. Instead of

advantages, participants spoke of motivations that made end-of-life planning seem increasingly relevant. This could be personal (e.g., the sense of one's mortality), dyadic (e.g., a spouse's health), or contextual (e.g., wanting to make decisions easier for others). Instead of disadvantages, participants described barriers that were also personal (e.g., reluctance to acknowledge death), dyadic (e.g., spouse's lack of interest), or contextual (e.g., legal cost).

Finally, the process described by participants was often non-linear and gradual. Interest in end-of-life planning may temporarily increase following an emergency health event or death of a family member, but then wane as the crisis recedes. Identifying the moment and circumstances that triggered action was often difficult. Rather than distinct stages as depicted in the TTM, the process leading up to end-of-life planning may be better represented as traveling along a continuum with loops backwards and forward.

In light of these observations, I propose the model depicted in Figure 4 to represent how married couples may engage in end-of-life planning, including advance directive completion.



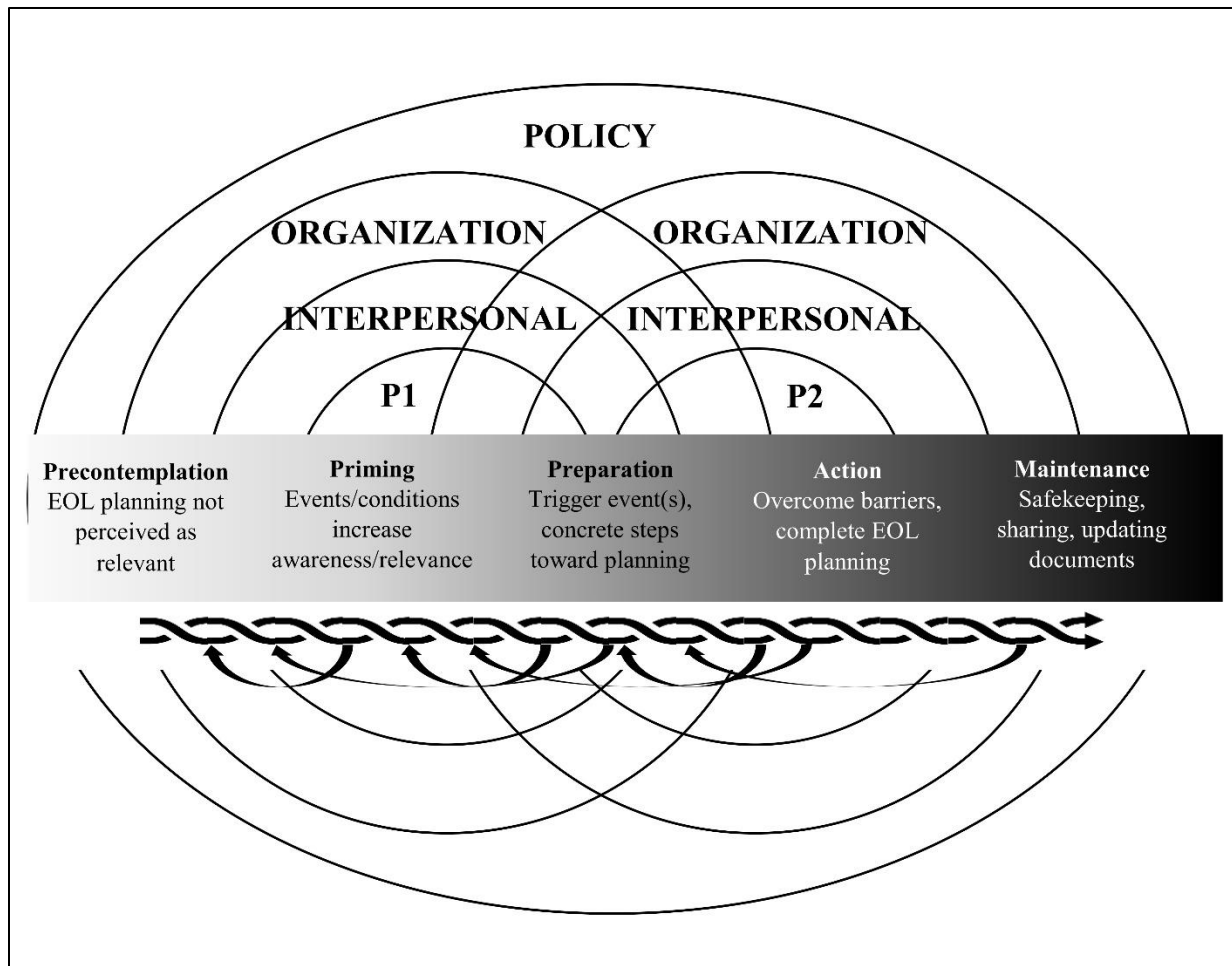


Figure 4. Relational model of end-of-life planning by married adults. Adapted from Prochaska et al., 1994.

When at the **Precontemplation** end of the continuum, individuals do not understand ACP or other end-of-life planning to be personally relevant or necessary for them at present. They may not be familiar with such planning or, if they are, they do not believe that they would benefit from engaging in end-of-life planning, perhaps because they perceive themselves as being too young or too healthy to need to think about incapacity or death.

Individuals may move into the **Priming** area of the continuum as life events gradually raise their awareness of end-of-life planning and make such planning appear applicable to them. Primers may include retirement, health problems, or crossing a chronological age threshold.

Experiencing or witnessing others' illnesses and deaths may also highlight the benefits of end-of-life planning, increase one's sense of vulnerability, or lead to a greater acknowledgement of one's own mortality. Someone in the Priming phase is planning to plan.

One or more triggering events shift people into toward the **Preparation** area of the continuum, during which they take concrete steps to engage in end-of-life planning such as researching legal services or obtaining forms. There may still be obstacles that need to be overcome, but the intention is to engage in some form of end-of-life planning in the near future.

Once the preparatory steps are taken and barriers overcome, individuals take **Action** and engage in end-of-life planning. They then move into the **Maintenance** phase in which they safely store any written records of their planning, inform others, and monitor their own preferences and situations to determine if they need to update their planning documents. Altered circumstances, loss of the documents, or changes in preferences may place an individual back in an earlier pre-Action part of the continuum.

***Intertwined arrows.*** End-of-life planning is carried out by individuals who must make their own decisions and execute their own planning documents. However, spouses influence one another's passage through the process of end-of-life planning as represented by the intertwined arrows. Couples may move in sync, but not always. When spouses find themselves at different points on the continuum, one may prompt the other to engage in end-of-life planning sooner than he or she would have otherwise. Alternatively, one spouse may hold the other spouse back from moving forward with planning. Or, each spouse may act alone consistent with where he or she is on the continuum at the time.

***Contextual levels.*** Passage through the process of end-of-life planning is influenced by the attributes of both spouses. This is represented by the two inner circles labeled P1 (person 1)

and P2 (person 2). Spouses also operate in separate but overlapping social contexts as represented by the concentric circles. At the interpersonal level, some relationships with family members, friends, and other acquaintances may be common to both spouses while others are exclusive to one spouse. Even in shared social relationships, the roles that husbands and wives play are likely to be different which may impact how these relationships influence their thinking about end-of-life planning. Likewise, husbands and wives interact with some of the same organizations, such as attending the same church, but also may have encounters with different entities, such as separate medical practices. Like interpersonal encounters, the nature of interactions will differ even in the same organizational context. For example, when a husband goes into the hospital, he engages with health care providers as a patient, whereas the wife interacts with many of the same health care providers as a loved one or caregiver. Unlike interpersonal and organizational contexts, the broader policy context, such as the PSDA, is the same for husbands and wives.

### **Limitations and Strengths**

A few limitations of this research should be acknowledged. The quantitative data lacked information about the timing of participants' ACP. Therefore, conclusions are limited to identifying the correlative associations between independent variables and advance directive completion. This is less of an issue for more constant variables such as education, but is a significant limitation for event-based factors such as prior hospitalization or outpatient surgery, although reverse causation is highly unlikely.

A second limitation applies to the quantitative and qualitative studies. Both relied on self-reporting of advance directive status. Participants may be mistaken about whether or not they have completed advance directives or may confuse advance directives with other end-of-life

planning documents such as DNRs, wills, trusts, or financial powers of attorney. This potential confusion was illustrated by Fred and Fran's uncertainty regarding whether or not Fran had completed an advance directive when she updated her will. Although I cannot address this limitation in the HRS data, if I conduct additional interviews in the future I may ask to see participants' advance directives just to confirm that they indeed have completed them.

A third limitation is the small sample size of the qualitative study. Phenomenological studies often rely on small samples. Nevertheless, I had hoped to recruit a few more couples, particularly participants who were non-White. I had also hoped to interview couples who had engaged in ACP in the past year, but recruitment challenges caused me to relax the time frame restriction. This meant that some participants' recollections of the events leading up to their end-of-life planning may have been diminished or altered by the passage of time. I view the present study as a pilot project upon which I can build with additional couple interviews, including those with other racial or ethnic backgrounds and those who engaged in ACP more recently.

There are also several strengths to highlight. To my knowledge, this is the first attempt to model advance directive completion by older married adults as a dyadic process influenced by both personal and spousal factors. The quantitative study used a well-respected, nationally-representative dataset with a large sample size and little missing data. These data were supplemented with qualitative interviews that confirmed the main conclusions and provided additional information about process and timing not available in the quantitative data. Although small and all white, the qualitative sample was diverse in terms of age, education, and health.

## **Chapter 9**

### **Implications and Future Directions**

This study provides evidence that advance directive completion by older married adults is a dyadic process influenced by personal and spousal factors. Furthermore, married couples occupy separate but overlapping social contexts that shape the end-of-life planning of both spouses. These findings have implications for both research and practice.

#### **Implications and Future Directions for Research**

The results call into question the usefulness of models that seek to predict or explain advance directive completion by older married adults with only individual-level variables. It may not be possible to formulate a reasonably accurate unified model that accounts for the end-of-life planning behaviors of both married and non-married persons because such a model cannot account for the dyadic nature of such planning carried out by the married participants but not present in the process of unpartnered adults. Rather than simply controlling for marital status, future studies may benefit from modeling separately advance directive completion of married adults and those who are not married.

Advance directives were just one part of a more comprehensive process of end-of-life planning for interviewees in the qualitative study. Other researchers have also observed that ACP and estate planning are parts of a larger, integrated process of end-of-life planning (Kelly et al., 2013; Su, 2008). Models seeking to predict or explain advance directive completion would likely benefit from the inclusion of variables relevant to other types of end-of-life planning, particularly estate planning and body disposition. Prior studies show that many of the variables associated with advance directive completion are also associated with estate planning, including race, education, age, and household income and assets (Carr, 2012c; Goetting & Martin, 2001; Kelly

et al., 2013; Su, 2008). Certain life events may trigger both ACP and estate planning, including the death of a spouse or a cancer diagnosis (Palmer & Bhargava, 2006). Other factors that have been linked to estate planning and may also lead directly or indirectly to advance directive completion include retirement, a substantial increase in net worth, home ownership, and anticipation of having assets at death (Goetting & Martin, 2001; Kelly et al., 2013; Palmer & Bhargava, 2006).

Building on the general finding that the APIM can be successfully used to model the advance directive completion of older married adults, other predictors that have been shown to be associated with ACP or end-of-life planning more broadly – e.g., death of a parent or loved one, cancer diagnosis, personality traits, preferences about life-sustaining treatment – could be tested for actor and partner effects as well as gender differences. If one spouse has high death anxiety, does that reduce the odds of both spouses' engaging in ACP? Does being married to someone who scores high on conscientiousness make one more likely to have an advance directive? When one spouse's parent dies, does that motivate or trigger end-of-life planning by both spouses?

Actor and partner effects on advance directive completion could be moderated by relationship quality or marital biography. Marital closeness may alter how influential spouses are on one another's end-of-life planning. Those in second (or third, or fourth) marriages, particularly if there are children from previous relationships, may perceive end-of-life planning to be more imperative but also more complicated. People who waited to marry until later life may approach their end-of-life planning in a more individualistic manner than long-married couples.

It would also be interesting to examine how similarities and differences between spouses influence husbands' and wives ACP. Rather than actor and partner effects, these would be joint effects of couple-level variables made up of a combination of husbands' and wives' characteristics. For example, building on the findings that a spouse's age and education are positively associated with one's own advance directive completion, the next step could be to look at whether and how the size of age or educational gaps may influence ACP.

A puzzle in the qualitative data is why events or circumstances motivated end-of-life planning but did not trigger action for some participants, while a similar event or circumstance directly led to engagement in end-of-life planning for others. Why did knee surgery, for example, cause Harold to do an advance directive but merely increase Bob's interest? A possible explanation is that end-of-life planning may be the result of an accumulation of experiences and conditions with the final event tipping the scale and triggering action. Rather than putting all independent variables into a linear equation to predict advance directive status at a single point in time, it may be more fruitful to model the "risk" of advance directive completion over time using event history or survival analysis (Cleves, 2008). When older adults are married, husbands' and wives' time trajectories are likely to be intertwined, so adding a temporal component makes analyzing ACP dyadically even more complex.

These potential explanations for the negative partner effects of poorer spousal health observed in the quantitative data could be further explored by controlling for spousal caregiving or by looking at longitudinal data to see if the likelihood of advance directive completion increases following the death of a spouse who was ill for a substantial period of time. Interviews with older adults whose spouses are suffering from poor health about the reasons they have or

have not engaged in ACP could shed additional light on the underlying mechanisms for the apparent negative relationship between spousal poorer health and advance directive completion.

While not the focus of this study, the question of why a substantial minority of the husbands and wives in the HRS reported different advance directive status would be worthy of further exploration. The interview data provide some possible clues. It may be that these couples did not engage in ACP as part of broader estate planning. Information about and assistance with advance directive completion could have been offered to only one spouse, such as at hospital admission. A person who faces resistance from his or her spouse may eventually elect to engage in ACP alone. Possibly a greater difference in age, education, or health status between spouses could explain incongruent ACP. ACP by only one spouse could also be the result of an “off-time” event (Neugarten & Neugarten, 1996), such as serious illness at a relatively young age, that triggers advance directive completion by one before the other is ready.

### **Implications and Future Directions for Practice**

Interventions to promote advance directive completion could potentially benefit from a recognition of the dyadic nature of ACP by older married couples. This could be as simple as providing a married patient two advance directive forms when he or she goes to the doctor’s office, hospital, or nursing home. Health care providers could offer to assist the patient and his or her spouse with completing their forms together. Educational materials and tools designed to help people to complete advance directives could be tailored to better address the perspectives and needs of married adults by, for example, including advice about how to talk to one’s spouse about engaging in ACP, presenting the benefits of ACP in relational terms (as opposed to emphasizing individual autonomy), and walking users through a joint decision-making process.



Particularly important to advocacy efforts encouraging end-of-life planning is the recognition that older married adults may face barriers that are internal (e.g., reluctance to acknowledge mortality), external (e.g., lack of financial resources), and/or relational (e.g., spousal resistance). It may be beneficial to inquire about these types of potential obstacles when discussing ACP with patients or clients and, if appropriate, to help find ways of overcoming them.

Critiques of the PSDA point to research showing that providing information to patients about ACP does not significantly increase advance directive completion. These studies tend to use a narrow time window between when patients receive information and measuring advance directive status. I found that older men who had been hospitalized or had undergone outpatient surgery in the past ten years (a much wider time frame than what is used in studies measuring the impact of the PSDA) were more likely to have advance directives, as were their wives. Hospitalization was a trigger for advance directive completion for only two of the eight participants in the qualitative study, but others talked about receiving information about ACP from hospital staff as well as being asked repeatedly about their advance directive status. As one participant expressed it, “They just plant a seed.” The PSDA mandates may contribute to the priming of older adults by gradually increasing awareness and making ACP seem more relevant even if hospitalization itself is not always the immediate trigger for completing an advance directive.

To date, much of the effort to promote advance directives has targeted patients in health care settings and focused exclusively on medical decision making. Meanwhile, those with financial means are encouraged and assisted by attorneys or financial planners to complete advance directives along with estate planning. Treating ACP as one part of a broader end-of-life

planning process could be a more effective approach because some older adults may be motivated by the perceived need to get their financial affairs in order rather than the need to plan for end-of-life medical care. Outreach efforts could involve health care providers and attorneys working in partnership to provide information and assistance in both medical and non-medical settings.

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## Appendices

### Appendix A: Advance Care Planning Study Interview Protocol

Date:

ID #:

Location of Interview:

Start Time:

End Time:

*Review consent forms. Explain terminology of advance directives (includes living will, durable power of attorney for health care).*

Approximate date of AD completion:

Questions	Prompts
1. Could you please tell me briefly about your family?	<ul style="list-style-type: none"><li>• Married? Length of marriage? First marriage?</li><li>• Children? Grandchildren?</li><li>• Are parents living?</li><li>• Siblings?</li><li>• Other close relatives?</li></ul>
2. Are you currently employed? What type of work do/did you do?	<ul style="list-style-type: none"><li>• How long have/had you done that type of work?</li><li>• How long have you been retired?</li></ul>
3. How did you learn about ADs?	<ul style="list-style-type: none"><li>• From whom? Where?</li></ul>

Questions	Prompts
4. How did it come about that you completed an AD?	<ul style="list-style-type: none"> <li>• Ever completed an AD before?</li> <li>• Even considered completing an AD before? How long did you consider? What do you think stopped you before?</li> <li>• What do you think prompted you this time?</li> <li>• What were the events that led up to it?</li> <li>• Did anyone encourage you? Discourage you?</li> <li>• Did you do any research beforehand?</li> <li>• Did you have any concerns?</li> <li>• How did you get the forms? How long did you have them before you completed them?</li> </ul>
5. [IF MARRIED] Does your spouse also have an advance directive?	<ul style="list-style-type: none"> <li>• Did they complete it at the same time that you did?</li> </ul>
6. Please set the scene for me by describing the process of completing the form.	<ul style="list-style-type: none"> <li>• Where were you?</li> <li>• Was anyone else there? What were they doing?</li> <li>• How long did it take?</li> <li>• What did you consider when you made your choices about what treatments you would or wouldn't want?</li> <li>• How did you choose your proxies? Did you consider other possible persons?</li> <li>• Did you discuss your choices with anyone in advance or during the process?</li> <li>• Did you find any aspects of the process difficult?</li> <li>• Did you coordinate your choices with anyone?</li> <li>• Did you complete any other documents?</li> <li>• What did you do with the forms after they were completed?</li> <li>• Did you discuss your decisions with anyone afterward?</li> </ul>
<i>Give participant timeline cards.</i>	

Questions	Prompts
<p>7. I am interested in what was going on in your life around the time you completed your AD. On each of these cards is something that may have happened to you or that you may have done. Please place any that happened in the past two years in the middle of the table.</p> <p>[IF MARRIED]</p> <p><i>[second stack, different color]</i></p> <p>Now please place any events or circumstances that happened to your spouse in the past two years in the middle of the table.</p>	
<p><i>Ask participant to group cards that refer to the same event. Then ask participant to organize the cards in approximate chronological order. Give participant poker chips.</i></p>	
<p>8. Looking at all of these events, could you place a chip next to any that in some way motivated you or made it more likely that you would complete your AD?</p>	<ul style="list-style-type: none"> <li>Is there anything else that motivated you? This could be something that happened in the last two years or earlier. <i>[Provide blank cards if needed.]</i></li> </ul> <p>[IF MARRIED]</p> <ul style="list-style-type: none"> <li>Would you say this additional event happened to you, to your spouse, or to both of you?</li> </ul>
<p>9. Which of these had the strongest effect on your doing your AD when you did? How did that influence you? <i>[Repeat for second most important, etc.]</i></p>	<p><i>Remove the chips as they are discussed and mark each card with a sticker indicating rank order.</i></p>
<p>10. Now place a chip on anything that made it less likely that you would do an AD or prevented you from doing one earlier.</p>	<ul style="list-style-type: none"> <li>Are there any events or circumstances not listed here that delayed or made it less likely you would complete an AD? <i>[Provide blank cards if needed.]</i></li> </ul> <p>[IF MARRIED]</p> <ul style="list-style-type: none"> <li>Would you say this additional event happened to you, to your spouse, or to both of you?</li> </ul>



Questions	Prompts
11. Which of these has the strongest negative effect on your motivation or ability to complete an AD? How did that influence you? <i>[Repeat for second most important, etc.]</i>	<i>Remove the chips as they are discussed and mark each card with a sticker indicating rank order.</i>
12. Just to make sure I understand, can you summarize for me the events or circumstances that led to you completing your advance directive when you did and not before? Feel free to arrange the cards to illustrate the process leading up to your completing an advance directive.	<ul style="list-style-type: none"> <li>• Did some events or circumstances happen before others?</li> <li>• How did earlier events or circumstances lead to or relate to later ones?</li> </ul>
13. When do you think is the right time to complete an AD?	
14. I just have a few more background questions.	<ul style="list-style-type: none"> <li>• Would you mind telling me how old you are?</li> <li>• What is your education?</li> <li>• How would you describe yourself religiously?</li> <li>• (if not evident) What is your race/ethnicity?</li> <li>• Would you say your current health is excellent, very good, good, fair, or poor?</li> </ul>
15. Is there anything else you would like to share? Is there anything you would like to ask me?	

**Write post-interview observations on back.**

## Appendix B: Card Sorting Exercise Cards

Self Events	Spouse Events
I retired	My spouse retired
I moved to a different home	My spouse moved . . .
I changed or lost a job	My spouse changed . . .
I was admitted into the hospital	My spouse was admitted . . .
I was diagnosed with an illness or condition	My spouse was diagnosed . . .
I took a big trip	My spouse took . . .
My health or fitness significantly improved	My spouse's health . . .
My health or fitness became significantly worse	My spouse's health . . .
I had a loved one become ill or die	My spouse had . . .
I had a near death experience	My spouse had . . .
I was a caregiver	My spouse was . . .
I made medical decisions for someone else	My spouse made . . .
One of my children moved further away	One of my spouse's children moved . . .
One of my children moved closer	One of my spouse's children moved . . .
I welcomed a new grandchild	My spouse welcomed . . .
I wrote or changed a will or trust	My spouse wrote . . .
I made my funeral arrangements	My spouse made . . .
I lost a pet	My spouse lost . . .
I had an accident	My spouse had . . .
I served as an executor or trustee of an estate	My spouse served . . .
I attended a presentation about advance directives	My spouse attended . . .
I had surgery	My spouse had . . .
I knew someone with Alzheimer's or dementia	My spouse knew . . .
I had a friend become ill or pass away	My spouse had . . .
I had a friend or family member move into a nursing home	My spouse had . . .
Someone I knew was placed on life support	Someone my spouse knew . . .
I talked with a doctor about life-sustaining treatment options	My spouse talked . . .
I turned 65 years old	My spouse turned . . .
I read or saw a media story about a patient on life support	My spouse read . . .